

# The health consultation experience for people with learning disabilities: A constructivist grounded theory study based on symbolic interactionism

Thesis submitted in accordance with the requirements of the University of Chester for

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“Yet it consoles me to have spoken to my doctor. I have often felt anxious about myself for perhaps being too proud to speak to anyone... And what had the doctor really to say? Nothing. But for me it was of importance to have respected the human relationship.”

Søren Kierkegaard, 1813-1855

(Kierkegaard, *trans.* Dru, 1958, p. 138)

## **Abstract**

**Aims.** The aim of this study was to explore the effects of the health consultation experience for people with learning disabilities, particularly in terms of their self-concept

**Background.** Annual health checks have been introduced as a reasonable adjustment for health providers to make in meeting the needs of people with learning disabilities, who experience significantly poorer health outcomes than the general population. Evaluation of the health consultation from the service user perspective can inform this service provision.

**Design.** A constructivist grounded theory approach, based on symbolic interactionism, was used to explore the meaning of the health consultation experience for the person with learning disabilities, and its effects on their sense of self.

**Methods.** Purposive and snowballing sampling was used to recruit 25 participants with learning disabilities through a GP practice, self-advocacy groups and a health facilitator. Nine individual interviews, three interviews with two participants, three focus groups ( $n=7$ ,  $n=5$  and  $n=3$ ), and an audio-recorded health check consultation were carried out (with two participants interviewed twice and four attending two focus groups), as well as a member check used to assess the resonance of the findings. Data collection was undertaken in different primary care trusts across the north west of England. Data were subjected to constant comparative analysis, using a symbolic interactionist approach, to explore all aspects of the health consultation experience and its effects on the self.

**Findings.** Current expectations, attitudes and feelings about health consultations were strongly influenced by previous experience. Participants negotiated their own reality within the consultation, which affected their self-concept and engagement with their health care. Respectful and secure health professional – service user relationships, developed over time, were central to an effective consultation. Perspectives on the consultation, and engagement within it, were co-constructed with a companion, who could help to promote the personhood of the service user with support from the health professional. Anxiety, embarrassment and felt stigma were identified as significant barriers to communication and engagement within the consultation.

**Conclusions.** People with learning disabilities have similar health consultation needs and expectations to other people, but may have more difficulties in engaging with the process and building trusting relationships with the health professional, due to previous negative experiences, anticipated stigma and loss of self within health settings leading to a fear of disclosure. This, combined with difficulties in communication and cognitive processing, results in less satisfactory outcomes persisting over time. The effects of triadic consultations are generally positive, particularly where relatives or health facilitators are involved. However, continuity of companion as well as health professional is needed, and more service user engagement should be supported. Fundamental attitude change by health professionals, supported by specific educational initiatives to enhance their understanding of the service user perspective, is needed to reduce health inequalities.

Participatory research by people with learning disabilities should inform future health care practice.

**Keywords:** constructivist grounded theory; symbolic interactionism; learning disabilities; professional-patient relations; health psychology; nursing; primary care; person-centred care.

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## ***Chapter 1: Introduction and Background to Research***

### **Rationale for the Research – The Rights of People with Learning Disabilities**

The idea for this thesis arose out of personal experience where miscommunication and perceptions about symptoms affected my own health outcomes. This made me wonder how people who have learning disabilities, and therefore limited communication skills, experienced their own health consultations when, as an experienced nurse, I was unable to communicate my own health needs.

### ***Structure of Thesis and Literature Review Strategy***

The structure of this thesis broadly follows the order in which the research was carried out. Thus, literature searches were carried out following analysis, related to the developed themes. This reduced the influence of received theory and supported the need to ground findings in the data (Glaser & Strauss, 1967). It also facilitated critique of the constructed theory within the context of the literature (Charmaz, 2006). As a consequence, some points in the background and rationale have been clarified, supported or revised in the process.. For the same reason, while I have discussed the background concepts known to me prior to data collection, I have not discussed any evaluations of current health service provision for people with learning disabilities until after the data analysis, and have returned to look at the health consultation literature in more depth. Within the constructivist grounded theory methodology, a traditional narrative literature review was carried out in relation to each theme. Using this systematic approach (Cronin, Ryan, & Coughlan, 2008) for each theme gave context to the findings and informed the analysis. The strategy for searching and reviewing the literature for this thesis initially involved searching the grey literature [not published in peer-reviewed journals] (Bettany-Saltikov, 2012) for Government reports, and other reports produced by disability organisations, particularly Mencap (a charity representing people with learning disabilities and their families). This represented the current policy and clinical approach to health care for people with a learning disability, identifying areas of agreement (although sometimes with little empirical evidence) and areas of controversy. Searches focused on literature related to health consultations, annual health checks and health outcomes for people with a learning disability. This literature forms the basis for the introduction (in Chapter one) of current health issues and provision for people with a learning disability, and was updated in May 2014, prior to submission of the thesis. The initial literature search also explored key theoretical constructs

underpinning the research question in terms of psychological needs in relation to health consultations. Databases relevant to nursing research were used (Cronin et al., 2008), see table 1 below.

Table 1: Initial literature search for background to study		
Database Searched	Search Terms Used	Limiters Used
CINAHL (Cumulative Index to Nursing and Allied Health Literature) Plus with full text	<u>Key words</u> "patient-centered care" AND "health" "patient compliance" AND "communication" "professional-patient relations" AND "communication" <u>Major headings</u> "mental retardation" <sup>1</sup> ; "patient satisfaction"	<ul style="list-style-type: none"><li>• Adult only</li><li>• Previous 10 years from year of search<sup>2</sup></li><li>• Peer-reviewed</li><li>• Journal articles</li></ul>
PsycInfo		
PubMed		
SocIndex		

The findings from these searches are mainly discussed in Chapter One.

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Chapter two explores the philosophical and methodological perspectives underpinning the research, focusing on the importance of using a constructivist grounded theory approach assuming the symbolic interactionist stance that we understand ourselves through the actions and communications of others towards us, and reinterpret ourselves and our value through these experiences. The practical barriers to carrying out this research are outlined, and methods for data collection are discussed. This is followed by a brief outline of how the data were coded and organised during the analysis, to identify the key themes constructed from the data that are then reflected in the following chapters. Thus, chapter three examines the theme of emotional security with the service provider, the factors that affect it, and its implications for inclusion in the consultation and health outcomes from it. The literature reviewed related to this theme was searched for as above using the terms "communication" AND "relationship" AND "health consultation", as well as "intellectual disability" OR "learning disability" AND health consultation. All literature reviews related to

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<sup>1</sup> An initial search on MH "mental retardation" and MH "health" was carried out in 2010, but this was not repeated again until after the initial phase of data analysis, to prevent preconceived theory affecting my interpretation of the data. By this time, the major heading "mental retardation" had been changed to "intellectual disability"

<sup>2</sup> Where relevant studies were found from other literature these were incorporated into the review, even if they were more than ten years old

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the analysis were completed in 2014. Chapter four analyses the role of the other within the health consultation, evaluating the benefits and limitations of the triadic consultation, and the specific consultation needs of people with learning disabilities relating to continuity of care across multiple mainstream service providers. Literature search terms included: “health action plans”, “health facilitator”, “acute liaison nurse”, “annual health check”, and “learning disability” OR “intellectual disability” AND “dual diagnosis”, as well as “triadic” AND “health consultation”. Chapter five explores the different barriers to communication that were expressed by service users, including incomplete understanding; anxiety (along with some strategies used to reduce it); embarrassment; and felt stigma around the body, sexuality, having learning disabilities, epilepsy, and having a mental health disorder or being associated with psychiatric services. The literature search strategy was specific to each final category, particularly “anxiety”, “embarrassment”, “stigma AND epilepsy”, all related to learning disability, but a general search was carried out on “embarrassment” AND “health consultations” as well. Chapter six examines the iterative nature of health encounters having a cumulative effect on the person’s self-concept, both within the health consultation and in terms of being worthy of positive regard by others. Chapter seven reflects on the methodological issues related to this study and evaluates it using Charmaz’s (2006) criteria for grounded theory research. Penultimately, in chapter eight, the overall findings from the study are set in the context of the literature, to evaluate its contribution to knowledge and make recommendations for future research. Finally, chapter nine identifies the implications of the consequent model of health consultations for people with learning disabilities for health professional practice, education and service provision.

### ***Human Rights and Healthcare for People with Learning Disabilities***

This first chapter identifies the importance of human rights in healthcare and healthcare research for people with learning disabilities, establishing the research perspective that disability is a social construct that can be used to undermine the rights of the individual. It then defines learning disability and outlines the historical health inequalities for people with learning disabilities, showing how discriminatory health provision led to inequalities in health outcomes, as evidenced by several influential reports and key policy documents. This leads to discussion of the development of registration and annual health checks for people with learning disabilities, supported by health facilitators and health action planning, in order to make reasonable adjustments for them to access mainstream health services. This supports the need for research into this service on the basis that it has been introduced to improve the healthcare experience and outcomes for

people with learning disabilities, but at the time this project began in 2008, little research had been carried out into health consultations for people with learning disabilities, so the rationale for annual health checks was theoretical. In a review of how the human rights of people with learning disabilities are met within current health and social care provision (Lawson, 2004), it was found that fundamental human rights were being routinely denied in small ways, often because service providers did not act in a way that promoted them. Examples from recent research were given in which service users had to request permission to use their own belongings, in which their rights to relationships were not considered when relocation was necessary, and in which their living environment exposed them to physical and emotional harm. Despite the four principles espoused by the Government's White Paper *Valuing People* (Department of Health, 2001), namely rights, independence, choice and inclusion, Lawson (2004) has concluded that the Commission on Equality and Human Rights is needed to meet the needs of "ordinary people with extraordinary needs" (Hubert, 2000, cited in Lawson, 2004, p. 11). In other words, if society is to meet the individual needs of people with learning disabilities, people need to change their attitudes towards disability.

The rights of people with learning disabilities, commonly based on O'Brien's accomplishments (O'Brien and Tyne, 1981), include the rights of choice, community presence and participation, competence and respect (Morgan, 2002). Choice means that not only are people given a verbal choice, but that they should be encouraged and supported to make choices even if their verbal ability is limited, or if they have not learned to make choices through lack of experience. The importance of visibility and involvement with people and activities within the community is a clear factor in social engagement for everyone, for it is very difficult to be part of society if you are separated by geography or lack of participation in social activity. This also means that people with learning disabilities should have access to the normal services and agencies within society, but that they may require additional support to use them effectively. It may seem clear that people with learning disabilities should access the same healthcare as everyone else, but they also need to obtain outcomes that are satisfactory for them and would be deemed equitable to other service users. This requires reasonable adjustments so that they receive healthcare according to their needs (Michael & Richardson, 2008). Competence is the opportunity to develop skills for independent living, whether social, communicative, psychomotor or procedural. In humanistic terms, it is being able to self-actualise or "become more of a person, more unique and more self-expressive" (Rogers, 1967), a necessary condition for

psychological well-being. The right to respect for individuals, and recognition that their needs may require unusual and creative approaches by service providers or employers, is not only necessary for social inclusion, but is essential for health service providers to meet people's health needs.

In *Valuing People Now* (Social Care, Local Government and Care Partnerships Directorate, & DH, 2007), the Secretary of State for Health reiterated the importance of:

“ensuring that people with learning disabilities can access mainstream services for health, housing, education and employment – the things that ensure equality of citizenship (p. 3).”

The focus of this research is the experience of healthcare provision for adults with learning disabilities, with particular regard to the relationship between the individual needs of the service user and the aims, approaches and attitudes of the service providers. At the start of this project, this was a poorly researched area (see *Setting the findings in the context of the literature*), although there were several reports, based on direct evidence and small studies of practice (see *Health needs and inequalities and the development of service provision for people with learning disabilities*), that identified several disadvantages in health and healthcare experienced by people with learning disabilities. This area is important not only in terms of human rights and patient satisfaction, but also, as I shall argue, in terms of health outcomes. If people with learning disabilities are being labelled as such in order to receive annual health checks aimed at making reasonable adjustments for accessing mainstream health provision, then they have a right to evaluate this service provision in their own terms. The key to this approach is to understand the experience through the narrative of individual service users with learning disabilities. This enables the researcher to discover how well their individual holistic healthcare needs are met. It also allows for exploration of how that individual's self-concept and self-esteem are affected by the process. Significant factors in meeting healthcare needs are the ability of the service user to communicate them to the health professional, and for the health professional to have the communication skills to facilitate that. In order to analyse some of these issues in depth, it is necessary to understand the context of health consultations for someone with learning disabilities. This includes understanding how someone is given the label of having learning disabilities, the identified inequalities in health and healthcare for people with learning disabilities, and how health service provision has developed for service users with learning disabilities.



### ***Definitions and Incidence of Learning Disability***

The American Psychiatric Association (2013) makes the diagnosis of intellectual disability (developmental) if the following criteria are fulfilled:

- There are deficits in intellectual functioning, such as in reasoning, problem solving, planning, abstract thinking, judgement, traditional academic learning, and experiential learning, assessed using a culturally appropriate, standardised intelligence quotient (IQ) test showing a score in the lowest 2.5% of the population (typically 70 or below).
- There are deficits or impairments in adaptive functioning, including being able to live independently and in a “responsible manner”, requiring additional supports to achieve at school, work or independent life. Standardised tests/questionnaires would be used to assess communication, motor skills, daily living skills, socialisation and behavioural issues.
- Intellectual or adaptive functioning problems were evident during childhood or adolescence.

In the United Kingdom (UK), both the *Confidential Inquiry into Premature Deaths of People with a Learning Disability* (CIPOLD, 2014) and Improving Health and Lives: Learning Disabilities Observatory use a similar definition, derived from *Valuing People* (Department of Health, 2001), to identify who is included in their research into the health and healthcare provision for people with learning disabilities:

“Learning disability includes the presence of:

- A significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with;
- a reduced ability to cope independently (impaired social functioning);
- which started before adulthood, with a lasting effect on development.”

(Department of Health, 2001, p. 14)

CIPOLD includes the Special Educational Needs labels of moderate, severe and profound learning difficulties in this definition, as they relate to generalised learning difficulty, but specific learning disabilities such as dyslexia would not be included. It identifies that the internationally recognised term is intellectual disabilities, with only the UK using learning disabilities. People with autism would be included in this definition if the person affected by

it also had a generalised learning disability, but people with Asperger's syndrome would not, as they have average or above-average intelligence. They go on to list eight inclusion criteria for their research (see Appendix 1). Consequently, the current research study uses the term learning disability and its *Valuing People* (2001) definition, while being aware that the term intellectual disability is gaining currency in the UK and can be used interchangeably.

Emerson and Hatton (2008) have estimated that 2% of the English population (children and adults) had learning disabilities, and that there were 828 000 adults with learning disabilities in England, of whom 177 000 were known users of learning disability services. The Government data suggested a larger number of 1.65 million, of whom 1.2 million have mild or moderate learning disabilities and 145 000 have severe or profound learning disabilities (Department of Health, 2001), but this difference was attributed to not considering the higher mortality rates in people with learning disabilities (Emerson & Hatton, 2008). Mansell (2010) has used the international term profound intellectual and multiple disabilities in his report *Raising our Sights*, synonymously with the UK term profound and multiple learning disabilities. This report, in which he identified best practice for care and challenges to improvement in care for the people included in this group, defines profound intellectual and multiple disability as someone having an IQ of below 20, plus multiple physical or sensory disabilities, such as visual, hearing or mobility impairments, epilepsy and autism, often resulting in mobility, communication and behaviour problems. They would therefore require high levels of support to perform the activities of living, but with help are able to form relationships, make choices and enjoy activities (Mansell, 2010). The number of adults with profound intellectual and multiple disabilities in England is set to rise from 16 000 in 2010 to 22 000 in 2026, largely due to an increasing birth rate (Emerson, 2009). The abilities and needs of all people, including those with learning disabilities, are highly individual and variable, but for the sake of understanding literature, policy documents and professional terminology, it is useful to be aware of different levels of ability, although there will be considerable diversity of need across all levels. Someone with a severe learning disability may use basic words and gestures to communicate their needs and wishes, and may require day-to-day support with their activities of living. Someone with a moderate learning disability will be able to communicate some of their wishes and needs, and may be able to carry out some daily living activities with support. Someone with a mild learning disability may manage life on a daily basis, possibly not even seeking support from services. However, they may require

support in understanding abstract or complex concepts, and even though they may have some basic writing and numeracy skills, will find it difficult to complete forms and judge complex situations (Hardie & Tilly, 2011) such as giving informed consent, without support (Goldsmith, Woodward, Jackson, & Skirton, 2013).

### ***Health Needs and Inequalities and the Development of Service Provision for People with Learning Disabilities***

#### **Health Needs and Health Inequalities of People with Learning Disabilities**

In addition to having healthcare needs in common with the general population, people with learning disabilities are more likely to experience additional ill health and disability (Lindsey, 2002). For example, people with Down syndrome (estimated incidence 1 in 750 people) are at greater risk of dementia (Kozma, 2008). The incidence of Alzheimer's Disease in people who have Down Syndrome is estimated at 8.9% for 40 to 49-year-olds and 25.6% for those over 60 years old (Coppus et al., 2006), so Kozma (2008) proposed that annual screening for Alzheimer's disease should be included in routine medical care for "older" people with Down Syndrome. A smaller UK study (Holland, Hon, Huppert, & Stevens, 2000) showed that about a third of adults with Down Syndrome had Alzheimer's disease, which is much higher than European, American and Asian general populations, where the incidence is less than 1% for people under the age of 75 years (Gilleard, 2000).

Overall, mortality rates are higher in people with learning disabilities than for the general population (Emerson, Baines, Allerton, & Welch, 2012). CIPOLD, which examined the deaths of all people aged four years and above with learning disabilities in the south west of England between 2010 and 2012 (Heslop et al., 2013), found that the median age at death of people with a profound learning disability was 46 years, for people with a severe learning disability it was 59 years, those with a moderate learning disability had a median age at death of 64 years, while for people with a mild learning disability it was 67.5. The median age at death for women with a mild learning disability was 65, compared with 83 in the general population, while for men it was 71, compared with 78 in the general population, suggesting that health status inequalities compared with the general population are greater for women with learning disabilities than for men with learning disabilities.

A recent report, *Health Inequalities & People with Learning Disabilities in the UK: 2012* (Emerson et al., 2012), based on a review of the current literature, found that there

were differences in health status between people with learning disabilities (LD) and the general population (GPn) in the UK (see Table 2 below).

<b>Table 2: Summary of inequalities in health status</b>			
Information based on Emerson et al. (2012) <sup>3</sup>			
<b>Disease Type</b>	<b>Differences (%)</b>		<b>Possible Reasons (if given) or Related Problems</b>
	<b>LD</b>	<b>GPn</b>	
Cancer	12-18	<b>26</b>	Lower life expectancy of people with LD
Bowel cancer	<b>48-59</b>	25	Partly, possible link with <i>Helicobacter pylori</i> infection, with high rates associated with institutional care. Reported problems with oesophageal-gastric reflux, constipation and dysphagia
Coronary heart disease	Not known – but cause of death in 14-20% of people with LD		Almost half of people with Down Syndrome have congenital heart defects
Respiratory disease	<b>46-52</b>	15-17	Increased rates of asthma. People with LD and asthma twice as likely to smoke. Over 50% women with LD and asthma are also obese
Psychiatric disorders	<b>Children 36</b>	Children 8	Reasons may be various. Additionally, the incidence of challenging behaviour in adults with learning disabilities is given as 10-15%, but across age groups, self-injurious behaviour can be as much as 27%

<sup>3</sup> Higher incidence highlighted in bold

Endocrine disorder: Thyroid	People with Down syndrome have 9-19% incidence of hypothyroidism		
Endocrine disorder: Growth hormone deficiency	People with profound learning disability at higher risk of short stature		Untreated growth hormone deficiency
Endocrine disorder: Diabetes	Higher rates of type I and type II diabetes in people with LD		Not given
Mobility impairments	People with LD who are non-mobile have 7 x the mortality rate than other people with LD. Partial mobility doubles mortality.		Not given
Injuries and falls	Higher rates than general population		Not given
Sensory impairments: Vision Hearing	8-200 times higher incidence in LD than GPn		Associated with Down syndrome. Poor uptake of screening in people with LD
	40% incidence	Not given	
Other areas of health concerns include:  Oral health – greater incidence in people with LD of gum disease, tooth decay and extractions  Women’s health – possible inappropriate use of types of contraception, ranging from sterilisation to different methods of hormonal contraception; less awareness of menopause  Sleep disorders – 9% of people with LD reported to have severe sleep disorders			

These increased health needs are significant in this thesis for two reasons: people with learning disabilities clearly have a greater need for both physical and psychiatric health interventions than people in the general population, so they are likely to require more encounters with multiple service providers, which will have a greater impact on their lives than people who do not have learning disabilities; and service providers need to be aware of the difference in health needs in people with learning disabilities to ensure that health concerns, behavioural changes and other suggestive symptoms are followed-up in order to

eliminate diagnostic overshadowing and reduce inequity in health outcomes due to ineffective health promotion and inadequate care.

### **The Development of Health Service Provision for People with Learning Disabilities**

In the 1970s, 60 000 people with learning disabilities lived in hospital, leading to a mistaken conception by mainstream health professionals that the health needs of people with learning disabilities were not their responsibility. When the institutions closed down, community learning disability teams often provided parallel health services to meet the needs of people with learning disabilities (Mencap, 2004) even though specialist hospitals had never been the sole providers of healthcare for people with learning disabilities (Lindsey, 2002). Consequently, access to mainstream services was restricted and health providers remained unfamiliar with the needs of people with learning disabilities (Mencap, 2004). The statement that “evidence of avoidable illness and premature death amongst people with learning disabilities is a major cause of concern for the Government” (Department of Health, 2001, p. 62) underpinned the demand for the CIPOLD Inquiry. This was supported by a Mencap report (2004) *Treat Me Right! Better Healthcare for People with learning disabilities*, which identified increased likelihood of premature death due to a higher incidence of disability-related disorders, such as epilepsy, dementia, schizophrenia and thyroid problems, and to social class inequalities (many people with learning disabilities live on benefits or are on a low income).

While there are some physiological reasons for premature death in some people with learning disabilities, inequalities in health and healthcare were clearly identified in *Valuing People* (Department of Health, 2001), the White Paper outlining the Government strategy to address the marginalisation of people with learning disabilities in all aspects of their lives. Among other things, this strategy included the development of learning disability nurses as health facilitators to work with primary care services, service users and their carers, and social services. Their role was to identify people with learning disabilities, to ensure they were registered with a general practitioner (GP), to develop health action plans (HAPs) based on the needs of the service user and to facilitate co-ordinated care for that person. (As health action planning, health checks and the health facilitator role are central to this research, they are discussed in *Health action planning and health facilitation* below). The White Paper also stated that the feasibility of a confidential inquiry into premature deaths would be explored and all mainstream hospital services were to be accessible to people with learning disabilities.

The Mencap report *Treat Me Right!* (2004) also found that people with learning disabilities sometimes experienced serious shortcomings in their healthcare. Reasons given included that GPs had not received additional training and felt inadequate in meeting the needs of people with learning disabilities, leading to reduced access to healthcare; and that people with learning disabilities reported fewer symptoms and illnesses. Health screening identified “high levels of unmet physical and mental health needs” (Mencap, 2004, p. 13). However, health professionals also made assumptions about people with learning disabilities, for example, that they could not speak, or that their behavioural problems or concerns were normal for someone with learning disabilities. Inpatient hospital stays left parents looking after service users full-time because ward staff could not manage their needs effectively, and carers reported discriminatory attitudes and inadequate care because people with learning disabilities were not valued. The report recommended that:

- People with learning disabilities should be involved in educating healthcare professionals not to discriminate against them.
- Equal access to healthcare should be supported by “longer and more accessible appointments”, “accessible information” and “identification of people who have learning disabilities”.
- Annual health checks and equitable access to health screening should be offered to all adults with learning disabilities.
- Uptake of health services should be audited and a plan to reduce health inequalities should be made.
- Hospitals should provide their legal duty of care to people with learning disabilities.
- There should be an inquiry into the premature deaths of people with learning disabilities.

(Mencap, 2004, pp. 31-32)

The Disability Rights Commission then produced a report (*Equal Treatment: Closing the Gap: A Formal Investigation into Physical Health Inequalities Experienced by People with Learning Disabilities and/or Mental Health Problems* (2006). This found that, compared with the general population, people with learning disabilities who had diabetes had less frequent assessment of their body mass index (BMI); if they had suffered a stroke, their blood pressure (B/P) was assessed less regularly; and uptake of breast and cervical screening was lower. They also found that, despite unmet health needs being found at health checks and annual follow-ups, these had still not been introduced in England and

Wales. Information on the health needs of people with learning disabilities was not being collected nor used to inform service provision, and simple adjustments, required by law, such as making appointments by email, providing “easy-read” information, and using text and telephone appointment reminders were not being made. Furthermore, people were sometimes being prescribed antipsychotic medication inappropriately for challenging behaviour, with a consequent risk to their physical health due to side-effects. Overall, they found that people with learning disabilities had reduced access to healthcare, were less likely to be referred for specialist care, and had higher morbidity and mortality, some of which was avoidable. They found that primary care provision was regarded as less than satisfactory by about 50% of service users with learning disabilities or service users with a mental health disorder (anyone who accessed psychiatric services but did not have learning disabilities) or their carers, despite the providers’ view that their provision was satisfactory.

The report (Disability Rights Commission, 2006) made a number of recommendations, including: the provision of incentive payments to GPs for annual health checks; promoting targeted health screening programmes; ensuring the prevention of diagnostic overshadowing (the assumption that health or behavioural problems are part of the learning disability) and discriminatory attitudes through nursing and medical education; and targeting healthy living support programmes at people with learning disabilities and including them in their delivery. It also recommended that people with learning disabilities should be offered the opportunity to have their disability noted on their records, along with their preferred adjustments, such as early or late appointments, longer appointments, appointment reminders, telephone consultations and accessible appointment cards. Additionally, they should be offered regular health checks, and specialist services should ensure that any antipsychotic medication was appropriately prescribed (Disability Rights Commission, 2006). Following on from their *Treat Me Right!* (2004) report, Mencap published *Death by Indifference* (2007), narrating the way that six people with learning disabilities had died, showing that their healthcare had been seriously deficient and calling for: an end to unequal treatment; increased knowledge of the communication and health needs of people with learning disabilities among health professionals; inclusion of family members in decision-making; greater understanding of mental capacity among health professionals; an end to inappropriate judgements of best interest, based on the spurious view that people with learning disabilities have a poor quality of life; and a streamlined complaints system. They renewed their call for annual health checks and demanded an inquiry into the deaths of the six people in the report (Mencap, 2007).



The *Healthcare for All* report was produced by the inquiry, headed by Sir Jonathan Michael, a senior NHS clinician and manager, following investigation of the circumstances surrounding the deaths of the six people cited in *Death by Indifference* (Mencap, 2007). It identified that diagnostic overshadowing, discrimination, lack of training and misconceptions about people with learning disabilities led to inadequate care, and that “high levels of health need are not currently being met and... there are risks inherent in the care system” (Michael & Richardson, 2008, p. 53). It therefore recommended the establishment of a confidential inquiry into the deaths of people with learning disabilities and a public health observatory for learning disability, in order to discover the extent of the problem and provide clinical guidance for health professionals. It recommended that service user views should be represented on Trust Boards (responsible for financial and clinical governance of the Trust), that health organisations should register people with learning disabilities so that they can collect data to track their pathway of care, and that the families of service users should be involved “as partners in the provision of treatment and care” unless good cause not to is demonstrated. (Michael & Richardson, 2008, p. 55). The report also identified that “acute liaison nurses” (although the term seems to be used synonymously with health facilitator) are helpful “to provide health facilitation or link working between and across primary and secondary specialised (acute hospital) care” (Michael & Richardson, 2008, p. 41). It recommended that provision should be made by primary care trusts to commission annual health checks and provision of liaison staff to “improve the overall quality of healthcare for people with learning disabilities across the spectrum of care” (Michael & Richardson, 2008, p. 54). An outline of the service provision response to *Healthcare for All* follows, which demonstrates the need to evaluate health consultations, as annual health checks are a cornerstone of making reasonable adjustments to reduce health inequalities and improve health services for people with learning disabilities. However, congruent with a grounded theory approach, evaluation of this provision is not addressed until the data analysis, to prevent preconceptions affecting the research findings.

### **Annual Health Checks, Health Action Planning and Health Facilitation**

In the 2008/9 contract, NHS Employers offered payments to GP practices who chose to take part in a voluntary direct enhanced service for service users with learning disabilities (NHS Employers, 2009). To take part, practices have to liaise with the local authority to create a register of all people with a moderate or severe learning disability, and the lead GP, lead practice nurse and practice manager are required to attend learning disabilities multi-

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professional education session, led by a health facilitator or community learning disability nurse. They are then required to provide an annual health check (the Cardiff template (Hoghton, 2010) is recommended), which should include: a review of physical and mental health (including health promotion needs), with appropriate referrals; a medication check; a review of co-ordination with secondary services; and, where appropriate, a review of arrangements for transitional care. Health records should integrate with the health action plan and the person, with their consent, should be supported by a relative or carer. Liaison should be with relevant education services, social services and learning disability services. Time allowed for this health check was not stipulated, but an aspiration payment of £50 per person identified on the register would be awarded, and a further £50 paid at the end of the financial year if the person had received a health check. Consequently, to avoid a “claw-back” of the funding, practices needed to see half of the patients on their register. In 2012/13, 52% of people with learning disabilities who were eligible for an annual health check received one (Glover & Niggebrugge, 2013).

*Valuing People* (Department of Health, 2001) required that all people with learning disabilities should have a health facilitator by June 2003 and health action plans by June 2006, and stated that “Responsibility for ensuring completion of the HAP will rest with the health facilitator in partnership with primary care nurses and general practitioners” (Department of Health, 2001, p. 65). It described the HAP as:

“...an action plan and will include details of the need for health interventions, oral health and dental care, fitness and mobility, continence, vision, hearing, nutrition and emotional needs as well as details of medication taken, side effects, and records of any screening tests.”

(Department of Health, 2001, p. 64)

In *Action for Health* (Department of Health et al., 2002), more guidance is given on HAPs, but the level of professional involvement with the service user is less than suggested in *Valuing People* (Department of Health, 2001), stating that health action plans can be facilitated by a health professional, support worker, family carer, friend or advocate. It sees a higher level role, which can be carried out by “a range of health professionals, managers and commissioners”, as being to liaise with services to audit practice, monitor outcomes and provide relevant education for service providers (Department of Health et al., 2002, p. 8). The goal of the HAP is to maintain and improve the health of someone with learning disabilities, and to ensure that they are linked to the services they require. It also provides

an audit trail of care. The plan should be completed with the service user and regularly reviewed to identify and record health targets, to support access to health services, including screening, and to assist with health promotion. It should also fit into their person-centred care plan if they have one. *Valuing People Now* (Social Care, Local Government and Care Partnerships Directorate, & DH, 2007), highlighted the importance of improved liaison between services for people with learning disabilities. It also identified the continuing failure to achieve targets for health checks and HAPs, and recommended further guidance related to service provision for HAPs. This guidance suggested that health professionals and families needed more support from health facilitators or community learning disability nurses in developing HAPs, and that more acute liaison nurses were also needed to promote inter-agency working.

The evaluation of health planning, health checks and the role of the facilitator in these reports has been mostly by auditing the number of people who have health plans and health checks, interviewing service providers and groups representing carers, or counting the number of referrals that are made from health checks. The *CIPOLD Report* (Heslop et al., 2013) identified that, of the people who experienced symptoms of being unwell before their death, 84% sought healthcare in a timely fashion, but of these, nearly half had difficulty accessing appropriate tests or investigations, and a third died with undiagnosed significant illness. National Institute for Clinical Excellence (NICE) guidelines had not been followed, particularly those for management of epilepsy, falls, prevention of venous thromboembolism and nutritional support. Delays in tests, diagnosis and treatment, combined with a failure to follow care pathways and, where appropriate, provide follow-up care, combined with a lack of co-ordinated services for people with complex needs, an absence of proactive care, a lack of advocacy and poor record-keeping, all increased the vulnerability of people with learning disabilities to premature death (Heslop et al., 2013). Clearly, the picture shows that the health of people with learning disabilities has not been as well cared for as that of other people, and addressing, monitoring and demonstrating improvement in healthcare all necessitate extensive record-keeping and audit procedures. However, this risks depersonalising someone with learning disabilities to a series of outcome measures, which may not tell the full story for them of how they experience healthcare. Additionally, this thesis will argue that many of the care deficits stem from the quality of the health encounter or consultation between the service user (and their carer) and the health professional. Satisfaction with healthcare is also an important aspect of evaluating care, but there are difficulties with how, if at all, this can be measured, and

whether or not those methods would be appropriate for people with learning disabilities. It is also important to identify which aspects of a consultation someone did and did not find satisfying, but people tend to globalise their attitudes towards an experience so it is either all good or all bad. So, the question of what is most important in a health encounter, and how we can evaluate that, will be discussed next.

### **The Concept of Patient Satisfaction, Health Outcome Assessment and Health Professional-Patient Relationships**

#### ***What is Patient Satisfaction and How is it Measured?***

With the stated aim of moving towards a health service for people with learning disabilities that is focused on individual need rather than being service-led (Department of Health, 2001), it becomes necessary to establish what people's needs are, and how well health services meet them. The concept that satisfaction is a product of discrepancies between patients' expectations of care and perceptions of what they receive has been attributed by Eisen (2007) to Gregory C. Pascoe, an organisational psychologist studying customer satisfaction, particularly with primary healthcare (Pascoe, 1983). There is some debate over the service user's ability to fully evaluate healthcare due to insufficient knowledge of its complexity, but Donabedian (1988) has argued that quality of care could be measured in a variety of ways, as long as the definition of quality was agreed first. Current quality outcome measures used by GPs include: specific audits (such as of the appointment system); recognised patient satisfaction questionnaires; assessment of patient recall; assessment of adherence to advice and medication; variation in prescribing; referral rates; ability to detect illness; and comparison of procedure outcomes (Simon, Everitt, van Dorp, & Schroeder, 2010). However, they pointed out that patient satisfaction questionnaires "often have low validity and reliability" and are "closely related to the psychological health of the patient", using the example that people with depression are likely to evaluate care more negatively (Simon et al., 2010, p. 84). While the causality of this example is open to debate (for example, it could be argued that people with depression are likely to experience less satisfactory care), it is important to explore the usefulness of measuring patient satisfaction with a questionnaire.

Most studies of patient satisfaction are based on questionnaire responses, with the aim of evaluating and improving healthcare services. Consequently, many studies do not adequately explore what patient expectations are, and therefore what causes dissatisfaction, making it very difficult to make appropriate changes in order to improve

services (Williams, Coyle, & Healy, 1998). Questionnaire studies of satisfaction tend to either lack sensitivity, making it difficult for healthcare providers to know how they can make their care more satisfactory for the patient, or mask dissatisfaction through non-response (Powell, Holloway, Lee, & Sitzia, 2004). While questionnaire design plays a part in this (Whitfield & Baker, 1992), it seems that the results may be skewed by the halo effect (Asch, 1946). This is where the patient's satisfaction with one aspect of care that is particularly important to them affects their responses to questions about other aspects of care. Conversely, if they are dissatisfied with one aspect of care that is particularly important to them, this may affect their other responses in the same direction. Although people may identify shortcomings in a service, they often express satisfaction with the service as a whole. For example, in a telephone interview study of 8119 people across Europe, satisfaction with doctors' communication skills was high, despite identifying some shortcomings in that area of care (Coulter & Jenkinson, 2005). Additionally, in interviews with 19 participants, 14 of whom were current or recent mental health service users, it was found that clients could have significant personal negative experiences of healthcare but still answer a validated client satisfaction questionnaire positively (Williams et al., 1998). So, using satisfaction questionnaires means that patients' views on care may not be fully voiced and consequently cannot be addressed. If one argues that the quality of the experience is important both in terms of being able to express health fears and preferred management, as well as in terms of satisfaction and health outcomes, then it would seem that even validated patient satisfaction questionnaires are inadequate for the purpose of service assessment.

In summary, patient satisfaction is a difficult concept to measure, and for the patient to explain, and it may be questioned how responsive it is to change in the service provided. For service users who may not be used to having a voice, such as in mental health services, it may be difficult to express critical views (Powell et al., 2004); and learning disability health service users might well be in a similar situation. Thus, it has been advocated that investigating people's reported experiences of healthcare, particularly focusing on aspects that have been problematic, can be more informative and useful in order to address any potential shortcomings in care. Since the 2004 GP Contract, GPs have been incentivised to achieve indicators of quality within a quality outcomes framework (QOF), mainly of a clinical practice nature, but also in terms of patients' perceptions of the quality of their care. Only two questionnaires are approved for this: the General Practice Assessment Survey (GPAS) and its successor the General Practice Assessment

Questionnaire (GPAQ). The GPAQ (Mead, 2008) attempts to measure patients' satisfaction with GP consultations (see Table 3 below) and is adapted from the GPAS, itself adapted from a longer and slightly different American questionnaire called the Primary Care Assessment Survey; unfortunately the GPAS was seven pages long and off-putting for patients so items were removed if they were highly correlated with other question responses (and therefore did not add to understanding). However, after consultation with primary care trusts, other items that practitioners felt were most important were added in. Interestingly, the question about patient satisfaction was removed, as it was not specific enough to provide information that would allow for improvement in GP practice (Mead, Bower and Roland, 2008).

**Table 3: Some questions from the GPAQ (Mead, Bower and Roland, 2008, e3)**

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| <p>9. The degree to which the patient feels involved in decision-making about his/her medical care</p> <p>10. The GP's knowledge of the patient's medical history</p> <p>11. The patient's trust in the GP</p> <p>12. The degree to which confidential information about the patient is respected and protected by practice staff</p> <p>13. The degree to which the patient is kept informed of the results of any tests and investigations</p> <p>14. Ability to get referral to a specialist when the patient feels it is necessary</p> |
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Currently, therefore, although patient satisfaction questionnaires may reflect what is known and can be improved, they do not allow for evaluation of intangible experience. As Donabedian (1988) has observed, while technical aspects of care can be assessed through audit of well-kept records, "we need to understand more profoundly the nature of the interpersonal exchange between patient and practitioner, to learn how to identify and quantify its attributes, and to determine in what ways these contribute to the patient's health and welfare" (Donabedian, 1988, p. 1748). Fitzpatrick (2007) has argued that the psychological model of patient satisfaction is not fully developed, as the expectation-satisfaction model is used in parallel with other approaches that focus on the extent to which care addresses the underlying psychological uncertainties associated with seeking health support. Thus evaluation of health checks for people with learning disabilities cannot be achieved purely through satisfaction surveys or focus groups, because a more complete model of the service user perspective in health consultations is needed, one which incorporates feelings and aims to understand their causes and effects within the consultation.

Satisfaction with healthcare is important from an ethical standpoint because of the aim for individualised healthcare, in which service users want more choice and control (Darzi, 2008). However, it is also important from a health outcomes perspective, because patient satisfaction and adherence to advice and medication are related (Ley, 1982). Adherence is an important outcome measure for healthcare because non-adherence increases morbidity and mortality, increases health service costs and costs to the economy in terms of production, and can increase the risk of resistant strains of disease due to drug resistance. Potentially, it could also skew the results of drug trials (Arbuthnott & Sharpe, 2009). Studies of satisfaction with communication, satisfaction with the consultation and satisfaction with composite indices of professional competence, personal qualities of the physician and costs and convenience of care, all found that approximately one-third of patients were dissatisfied with their consultation. In all studies, satisfaction was related to their adherence to medication and advice (Ley, 1982). In their meta-analysis of studies on adherence in healthcare, Martin, Williams, Haskard, and DiMatteo, (2005) identified cognitive factors, interpersonal factors (particularly trust in the physician), patient involvement and participatory decision-making, patients' attitudes towards their health, cultural variations and depression as being significant predictors of adherence to health promotion or interventions. Trust was found to exceed other factors in terms of patient satisfaction and adherence to care, with significantly higher adherence rates where trust in the physician and the physician having knowledge of the patient as a whole person are combined. Clinical depression in the patient was the most significant determinant of poor outcome, which itself is often undiagnosed or ineffectively treated due to poor doctor-patient communication (Martin et al., 2005).

In an early study of problems with doctor-patient communication by Korsch and Negrete (1972), where mothers and children attended a local emergency department, it was found that 38% of mothers had complied with medication administration to the child only in part, and 11% not at all. (It is useful to note here that while the terms concordance or adherence are usually used in this country to denote agreement between patient and doctor on the aims and means of intervention, compliance is used to mean that the patient conforms to the medically prescribed treatment. In older articles, and particularly in North America, the term compliance is comprehensively used). There was a strong correlation between the mothers' expressed satisfaction with the doctor's behaviour in the visit and their compliance with instructions. More importantly: "The most severe and most common complaint of the dissatisfied mothers was that the physician had shown too little interest in

their great concern about their child” (Korsch & Negrete, 1972, p. 66). Despite this important finding related to empathy, later research focused on the more behavioural (and therefore easier to address) aspects of communication. In particular, Ley has identified key aspects of communication that influenced patient satisfaction, comprehension and adherence, focusing on pragmatic methods to improve communication and adherence. These included cognitive approaches to aid memory of information, incorporating behavioural cues from the person’s lifestyle and identifying any relevant health beliefs that could affect compliance (Ley, 1997). In a study of GP consultations (Kincey, Bradshaw & Ley, 1975), most patients’ self-reported compliance was high, with upwards of 80% of patients understanding and being easily able to comply with medical interventions and advice. Their exploration of satisfaction was largely limited to patient waiting times and to patients’ understanding and satisfaction with communication, and focused, pragmatically, on patients’ ability to understand what the doctor told them. Problematically, they also excluded people whom the doctors designated as unsuitable for interview: those who had “psychiatric problems, notably anxiety neuroses or mild chronic psychotic disorders, those suffering from bereavement anxiety/depression and those with emotional-sexual problems” (Kincey et al, 1975, p. 560). Consequently, this study omitted people for whom satisfaction has been reported as low (Martin et al., 2005).

Questionnaire-based studies investigating personality “fit” in the doctor-patient relationship have been unable to reduce that affective component of the consultation to a measurable model. Auerbach et al. (2002) used the NEO-Personality Inventory (McCrae & Costa, 1997) – a trait questionnaire, exploring facets such as extraversion, neuroticism, openness to new experience, agreeableness and conscientiousness – to look for a relationship between health outcomes and personality in 54 people attending a diabetes clinic. They also used the Health Locus of Control Questionnaire (a tool to measure the extent to which people believe they have control over their health) (Wallston, Wallston, & DeVellis, 1978), questionnaires to measure interpersonal behaviour (in terms of dominance, submission, friendliness and hostility), a perceived health scale to measure the degree to which individuals felt capable of managing their diabetes, and a health opinion survey to look at preferences for self-treatment and behavioural involvement in healthcare, as well as health-related information seeking. They also used a patient satisfaction questionnaire (Howorka et al., 2000). They then compared the results of all these questionnaires with levels of glycosylated haemoglobin (HbA1C) in the blood, an indicator of long-term control of blood sugar levels over a series of outpatient visits. The findings



were largely inconclusive, although they did find a statistical relationship between positive health outcomes of lower blood sugar levels and patients who preferred to take control over their diabetes. Patient satisfaction was only predicted by their perceived level of competence in managing their diabetes – the more competent they felt, the less satisfied they were with their treatment. Better blood sugar control was achieved when the physician perceived the patient as being more controlling and less submissive, while poorer control was related to the patient perceiving the doctor as more hostile and also when both parties perceived each other as having similar levels of controlling behaviour – where one or other was mutually perceived to have a complementary level of control or submissiveness, the blood sugar control was better.

In a follow-up study, Campbell, Auerbach, and Kiesler (2007) have used similar measures to assess patient satisfaction with occupational health doctors in an American university. They were not able to replicate the finding of a relationship between patient satisfaction and adherence, which they ascribed to the self-report of adherence not being an objective outcome measure. Their findings that patients preferred submissive doctors contradicted the earlier study, which they explained in relation to the relative lack of severity of the conditions as well as the educational level of the participants. They did replicate the relationship between a perception of the doctor as hostile negatively correlating with patient satisfaction. The methods used in both of these studies is unlikely to produce consistent results, as there will be other, confounding effects that are not directly captured in the data collection tools, due to the complexity of human interaction. Therefore, it is not surprising that their findings are contradictory.

These studies demonstrate how difficult it is to reduce personalities, interactions and reasons for patient satisfaction down to a set of numbers based on questionnaires, or even a content analysis of a consultation. A basic problem with all the questionnaire studies was that they narrowed the focus of the question about the relationship between patient satisfaction and health outcomes before the concept of satisfaction itself has been fully understood. In addition, any use that health professionals can make of new knowledge in this area has to involve understanding that can bring about attitudinal change in order for it to improve the service user experience. Mechanistic models that reduce understanding to simplistic relationships between narrowly and poorly defined variables are not helpful to practitioners. So, patient satisfaction is important from a service evaluation and ethical perspective, but it is difficult to measure, and the attempt to find simplistic relationships with other measurable variables has done little to move knowledge forward.

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However, another reason why patient satisfaction is important is because there is a known relationship between stress and reduced immunity, which can affect wound healing, vulnerability to infection and even cancer (Kiecolt-Glaser, McGuire, Robles, & Glaser, 2002). This body of research has traditionally used participant report of stress levels, or matched cohorts with a specific difference of stressor, and related them to physical health outcome measures in order to identify a causal relationship between the two. For instance, caring for a relative with dementia has been shown to delay wound healing (Kiecolt-Glaser, Marucha, Mercado, Malarkey, & Glaser, 1995), while examinations stress in students reduces the number of T-lymphocytes (white cells that mediate the immune system's response to antigens), including CD4 T-lymphocytes which manage the response to bacteria, fungi and viruses (Marketon & Glaser, 2008). These cells are damaged by HIV infection, so their levels are a marker of its severity, with higher levels being associated with better health.

These two areas of research – psychoneuroimmunology and patient satisfaction with healthcare – have now become linked. It was suggested that “patients have differing expectations for specific consultations” (Weinman, 1997) and that an important predictor of patient satisfaction was for doctor and patient to be in agreement about the desired outcome for the consultation; this is known as concordance. Elwyn et al. (2003) validated a tool to assess the amount of patient involvement the GP encourages within the consultation, and argued that, in addition to some extra consultation time, GPs could increase the amount of patient involvement in their consultations to improve concordance (Elwyn et al., 2005). This tool was modified to assess concordance with treatment change in the care of people with HIV/AIDS (which was greater than in Elwyn's 2003 GP study) and its relationship with physical health outcomes (Clucas et al., 2011). A significant positive relationship was found between greater levels of concordance, better quality of life, greater adherence and a higher CD4 cell count both at the time of the treatment change and 6-12 months later, but a causal direction could not be assumed. Thus, concordance is related to measurable physiological health outcomes in people with HIV/AIDS (Clucas et al., 2011), while stress impairs the body's response to infection and cancerous cells (Kiecolt-Glaser et al., 2002), so a satisfactory consultation can, in itself, be therapeutic, whereas an unsatisfactory one could directly impair well-being, as well as damaging future communication. These studies all contribute to our understanding of a number of factors involved in the outcomes from health consultations, and suggest some ways in which they might do so, particularly in terms of the importance of mind-body interactions and therefore person-centred communication in health consultations. They suggest that

concordance in consultations is not just a way of improving behavioural health outcomes, but also an integral factor in the therapeutic management of a person's health. However, the competing perspectives and lack of clarity over what leads to better health outcomes suggest the need for a more in-depth qualitative study of the service user experience, to achieve a more integrated understanding of the process.

### **The Effects of Person-Centred Communication on Health Outcomes**

The development of concordance in a consultation requires a degree of empathy, which affects the type of communication style the healthcare practitioner needs to use. The traditional medical model approach involves eliciting the primary reason for seeking a healthcare consultation, then narrowing down the questioning to pinpoint the precise health concern. Levenstein, McCracken, McWhinney, Stewart, and Brown (1986) have suggested that doctors' focused questions, which are aimed at eliciting the information they require to make a diagnosis, may result in important information being missed in a consultation. They have argued that this disease-centred method should be replaced by the patient-centred method of consultation, which they based on Rogers' person-centred counselling approach:

“...it is the client who knows what hurts, what directions to go, what problems are crucial, what experiences have been deeply buried. It began to occur to me that unless I had a need to demonstrate my own cleverness and learning, I would do better to rely upon the client for the direction of movement in the process.”

(Rogers, 1961, pp. 12-13)

Levenstein et al. (1986) have suggested that following the patient's cues could yield important information about symptoms or concerns that the patient had, but needed encouragement to voice. This would allow the doctor to explore the issues with the patient, leading to testing, treatment, or a reassurance that the symptoms were explicable and not a threat within the context of their life and health (see *Cues and prompts in consultations* for further discussion). In an observational and interview study of patients' consultations with their GPs (Barry, Bradley, Britten, Stevenson, & Barber, 2000) patients were found to have a large number of issues or “agendas” that they did not voice, of which the doctor therefore was not aware and could not address. This resulted in patients leaving with

prescriptions they did not want or use correctly, patients who left with anxiety, and a general mismatch between patient expectations and doctors' views of patient expectations:

“Doctors may overestimate the extent to which patients are primarily concerned with medical treatment rather than with gaining information and support”.

(Barry et al., 2000, p. 1246)

Doctors are often inhibited by the time they have available to them, as a person-centred approach generally results in a longer consultation, although over a long period such care is likely to be more cost-effective in terms of appropriate testing and referral (Epstein, Franks, Shields, et al., 2005b). Research on non-verbal behaviour in consultations suggests that non-verbal behaviours associated with femininity such as a longer gaze, a softer voice, smiling, gesturing and leaning forward, may improve patient satisfaction. The conclusion, although not able to give a straightforward set of satisfactory behaviours, suggests they can be taught (Mast, 2007). This is misleading, as non-verbal behaviours are generally related to the individual's inner attitudes and research has shown attempts to improve non-verbal communication in medical students to be unsuccessful (Ishikawa, Hashimoto, Kinoshita, & Yano, 2010). However, there is little research purely on the teaching of non-verbal behaviours as most communication education for health professionals is related to a set of attitudes as well as behaviours, requiring more comprehensive skills teaching and assessment strategies (Bylund, D'Agostino, Ho, & Chewning, 2010; van Es, Wieringa-de Waard, & Visser, 2013). Non-verbal behaviours are important in a relationship because they are less consciously considered than verbal behaviours and deliberate actions. Consequently, they are a greater key to understanding the intentions and attitudes of the other person. They are often subtle combinations that cannot be easily unpicked, as they are observed with other indicators and signs that are interpreted by the service user through the prism of that person's previous experiences and understanding. Where people try to “learn” appropriate non-verbal behaviours, they may give other cues that show these are not authentic, thus defeating their aim.

Fiscella (2002) has identified the importance of a collaborative approach to care, particularly in comparatively disadvantaged groups within society. He has identified the core components of patient-centred care as being:

“...consideration of the patients’ unique experience of illness...; incorporating the patient’s psychosocial context into assessment and treatment; establishment of common ground between the patient and provider...”

(Fiscella, 2002, p. 366).

He also suggested a framework for the consultation which requires the healthcare practitioner to establish a rapport with the patient and find out what they want from the consultation, then to find out what their perspective is (similar to identifying the patient’s agendas), then to demonstrate empathy with the patient in terms that show the practitioner wants to understand and assist with their health needs (in an holistic sense) and finally, ensuring that any barriers to adherence with advice are explored, including that advice and interventions are understood and explaining the benefits that they should bring (Fiscella, 2002). Andén, Andersson, and Rudebeck (2005), in their phenomenological interview and focus group study into patients’ perceptions of recent GP consultations, found similar effects, in that people found the change in self-perception arising from greater knowledge of their problem, or from a cure or relief from symptoms, or through adjustment and development of strategies for coping with their condition, to be important outcomes of their consultations. They also found that gaining understanding of their problem from the consultation was fundamental to a positive outcome, while a cure or remedy was not seen to be the most important aspect of the consultation. Patient satisfaction was generally related to all other categories, but mainly to understanding gained from the consultation. Confirmation of their experience, even with a serious diagnosis, was a significant positive outcome of the consultation.

A discussion of the self, self-concept, and how they alter in response to interaction with others can be found in *The role of symbolic interactionism within grounded theory*. An explanation of how Rogers’ theory of the self relates to a humanistic model of health professional-service user interactions is included here as part of the background to this study. Person-centred communication is based on the humanistic psychological theory of Carl Rogers (Rogers, 1961). He suggested that individuals have a natural need to fulfil themselves, called self-actualisation, and that if that tendency is thwarted, the individual becomes unhappy and loses mental well-being. He suggested that people needed to feel psychologically, as well as physically, secure, in order to self-actualise. Those who were concerned that others might judge them negatively or not approve of them would be less

likely to attempt growth or change for fear of failure or disapproval. He suggested that even people who had developed a mistrust of others through their earlier experiences might be able to self-actualise within a trusting relationship. He considered the necessary attributes for a trusting relationship to be: unconditional positive regard (where the therapist avoided judgement of the client's disclosures, enabling the client to achieve a level of honesty and self-acceptance); genuineness (where the therapist is sincere in his/her acceptance of and positive regard for the client, and is honest in their relationship); and empathy (where the therapist tries to understand the world from the client's point of view). This refers back to attachment theory (Bowlby, 1967) and the idea that the first primary relationship of one's life forms a pattern for all future relationships by creating an internal working model of the main caregiver, which is complemented by a model of the self. This suggests that a child who receives love and attention develops higher self-esteem, seeing themselves as worthy of that love, whereas a child who is encouraged to be self-contained and independent and is discouraged from expressing their feelings may feel less loved and therefore less worthy of love. These feelings of self-esteem may be factors in the relationships within the health consultation for all involved, and could contribute to some health professionals being perceived as more person-centred than others, as well as to service users and carers feeling more or less able to trust the health professional.

However, Rogers' theories were about lifelong development. He contended that conditional positive regard, in which a child is only valued when their behaviour is deemed acceptable by the main caregiver, results in the child not only having a low self-esteem, and a large gap between the ideal self and self-concept (see *The role of symbolic interactionism within grounded theory*), but also in the child being fearful of engaging with new experiences and ways of behaving, in case they "failed". Nonetheless, Rogers asserted his theory of life-long development meant that using person-centred therapy or counselling could change a negative view of the self within a relationship to a more positive one, by giving the person a safe environment in which to experiment with being the way they would like to be without fear of disapproval. In turn, this more positive self-concept would allow the individual to seek and develop more rewarding relationships outside the counselling environment in which they would be able to continue to grow as a person. The key point about person-centred theory from a health interaction perspective is that, if the person feels secure within the consultation relationship, they will feel able to express their beliefs, concerns and fears without being worried that the health professional will disapprove of them. This means that the professional can understand the holistic needs of

the person and, where possible, address them within the care interaction. Conversely, where the person perceives a lack of unconditional positive regard, they may feel reluctant to disclose some information. This is supported by a questionnaire study by Beach, Roter, Wang, Duggan, & Cooper (2006) that looked at self-reporting of respect of the doctor for the patient, and the patient's perceptions of how much doctors respected them. The study found that patients could accurately assess how much their doctor respected them. In addition, an independent analysis of the consultation found that patients whom doctors respected were given more information, suggesting a possible mechanism between a more satisfying consultation and a better health outcome. While it is difficult, sometimes, for even a health professional to feel universally benign without reference to their own feelings, Rogers argues, from theory and his own experience of teaching, that "it is almost certainly more constructive to be *real* than to be pseudo-empathic, or to put on a façade of caring" (Rogers, 1969, p. 113).

Levenstein et al. (1986) described a model of patient-centred care in which the doctor's aims for the consultation (the doctor's agenda) were described in terms of taking a history, making a physical examination and ordering tests in order to make a diagnosis and management decision. The patient's aims, however, were described in terms of expectations, feelings and fears in order to understand his or her illness experience. The traditional approach within the consultation, they argued, took a disease-centred approach where the doctor, as expert, asked focused questions aimed at eliciting specific information in order to rule out irrelevant diagnoses and narrow the problem down to a small number of possible diseases. They proposed that, while it was necessary for the doctor to follow the differential diagnosis pathway, it was also essential for the doctor to empathise with the patient and see the illness from his or her perspective in order to understand the patient's own agendas within the consultation. They argued that, without this understanding, the doctor could miss important information that might aid not only in diagnosis, but also in patient satisfaction and compliance with health interventions. In one study (Winefield, Murrell, Clifford, & Farmer, 1995), where patients were briefly questioned about their health prior to the consultation and then the consultations were categorised by content, out of 243 consultations, 101 were found to be straightforward. However, there was a strong correlation between those doctors found to be patient-centred, and those interactions found to be psychosocial (rather than complex or straightforward). Since correlation does not indicate causality or direction, it is possible that the patient-centredness of the doctor allowed the patient to express their psychosocial needs more

easily. Again, the focus of this study is so narrow that insight into the reasons for the findings is lacking. More understanding was gained from a qualitative study of patient agendas in GP consultations (Barry et al., 2000). Patients were interviewed before their GP consultation to identify their agendas, which included asking what made them decide to see the doctor, a description of their symptoms or illness, a discussion of what the patient thought might be wrong and what their illness fears were, and what they hoped the doctor might do and did not want the doctor to do. The researchers also asked about possible outcomes and other problems (generally emotional and social) they might ask the doctor about. These agendas were then compared with the agendas expressed in the consultation: there was a mismatch between the doctor's biomedical concerns and the, often unspoken, real world concerns of the patient. The consultations were recorded to identify whether the doctor questioned the patients' agendas and what agendas were not commonly raised. Out of 35 patients, most had five or more agenda items, but only four expressed all their agendas in the consultation.

The researchers (Barry et al., 2000) then interviewed patients a week or so after their consultation to explore its outcomes, with a focus on medication adherence. Out of 35 consultations, 14 (40%) were found to have problem outcomes, in all of which at least one of the problems was related to an unvoiced agenda item. One woman was worried that her menstrual problems might be cancer-related (as she was in remission), but this was not picked up in the consultation, so her fears were not addressed. In addition, she was unsure whether her symptoms were related to the menopause, and despite oblique references to it in the consultation, the issue was not addressed because the doctor dismissed it medically, without telling her. The GP prescribed hormone replacement therapy, which the patient did not take because the GP did not order a blood test and she did not trust his diagnosis. Her cancer specialist advised against the treatment. In this case, not only has the consultation been ineffective, but it has left the patient's trust of the GP diminished. In another case, a 28-year-old man was concerned about breathing difficulties following a broken nose, and was worried about poor outcomes from corrective surgery (which his friends had warned him about). He mentioned a cold to the GP, who prescribed antibiotics and did not discuss possible side-effects. So, when the man experienced side-effects, he stopped taking the antibiotics. He also did not get any information about his nose or the risks and benefits of surgery.

In their discussion Barry et al. (2000) suggested that patients are inhibited from expressing their agendas fully due to the biomedical model within which both patient and

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doctor interact, and even then, patients did not reveal all their symptoms. This mismatch of agendas was found to cause problems with adherence to medical advice or interventions. The authors argued that previous studies (including Winefield et al., 1995), which did not carry out open interviews of the patients prior to the consultation, would have missed these agendas and seen most of the consultations which followed as straightforward. They identified complex psychosocial and biomedical issues in the pre-consultation interview, which patients generally did not disclose in the consultation. They recommend that doctors take steps to encourage patients to fully articulate their needs and that research is carried out to facilitate this.

The body of research reviewed so far has looked at why patient satisfaction is important from a values-based service evaluation perspective, and how it affects adherence and even physiological well-being. However, there is little discussion of the effects of health encounters on self-concept, and how perceptions of the attitudes of the health professional towards the service user in the consultation may affect relationships in future health consultations, with consequent effects on thoughts, feelings and behaviours related to help-seeking, disclosure and engagement in healthcare. This thesis aims to explore this specific aspect of health consultations, but particularly in relation to people with learning disabilities.

### **People with Learning Disabilities – Social and Healthcare Experiences and Interpretations**

Inclusion in care consultations affects the way people with learning disabilities view themselves. Kelly (2005) found that some social workers communicated with parents and professionals, such as a speech therapist, rather than communicating directly with a child with learning disabilities about their needs. Some of the children questioned felt that when they were asked their views it was in inappropriate settings, possibly suggesting that it reinforced negative views of their difference from other children. When professionals decided to exclude children with learning disabilities from their care reviews, this decision was often supported by the parents, in the belief that their behaviour would disrupt the process, and that they would not understand the encounter. Only five parents out of the 32 interviewed expressed the desire for their child to participate in this process. Excluding children with learning disabilities from the decision-making process and focusing on the negative aspects of disability and impairment meant that professionals and parents were contributing to a negative construct of the self as a disabled person. That is, they behaved

toward the children as though they were unable to contribute to making decisions about their own lives, making the child feel incapable and diminished because of their disability. However, in their own words, the children were capable of expressing their thoughts and feelings and had similar life goals to other children. Parents, professionals and other children all transmitted their attitudes to the disabled child in different ways (although some parents did not think their child realised they had a disability), leaving the child with a mixture of views ranging from being limited, to being different, and relating to terms such as “mongol” or “autism”. This research (Kelly, 2005) identified a relationship between the attitudes of parents and professionals towards the disabled child and the child’s self-concept. It highlights the importance of enabling the person with learning disabilities to develop a sense of self-efficacy through involvement in decision-making processes about their own life. It demonstrates, on a practical level, that children with learning disabilities are able to express their thoughts about the effects of impairment and disability on their daily lives. This active social interpretation of having learning disabilities, its effects on consultations with professionals, and the importance of those consultations for the individual and their engagement with the encounter, should therefore be amenable to study. By interviewing people with learning disabilities about their experiences in healthcare consultations, more should be learnt about the effects those episodes have on the service user’s self-concept. Self-concept is important for two reasons: firstly, because it affects the person’s self-esteem and therefore psychological well-being, but secondly, and fundamental to the quality of healthcare, because it affects the negotiation within the health consultation that culminates in a diagnosis, management plan and ultimately, health outcomes (see *The role of symbolic interactionism within grounded theory* for further discussion of the self and self-concept).

Annual health checks are now a requirement in terms of making reasonable adjustments to meet the health needs of people with learning disabilities (Disability Rights Commission, 2006). The introduction, for people with learning disabilities, of individual surveillance and examination for medical and social care can impinge upon their freedom, invade their privacy and reduce their ability to make decisions (McIntosh, 2003). This assumes that the process of identifying and recording all individuals with learning disabilities can be seen not as a benign or neutral act, but as a “trap” to limit and control one’s options in exchanges within a power-based encounter (Russell, 1993). The professionalisation and rationalisation of care leads to the objectification of service users (McIntosh, 2003). If that argument is applied to the Health Action Planning process, it is

possible that people with learning disabilities may have their perceived health needs (from a professional viewpoint) met at the expense of their social independence and individual self-concept. As pointed out by Gates (2003), the requirement for all people with learning disabilities to be identified and have HAPs results in labelling (a green sticker on the notes or, in electronic systems, a red flag) and possibly other, unforeseen, consequences. The only way of examining this question in relation to people with learning disabilities is to find out whether they have a role in identifying and prioritising their care needs, or if the experience of health consultations tends towards reducing their sense of self.

Charmaz (1983) has found that people experiencing chronic illness experienced a loss of valued self-images, which were not replaced with positive ones, and it is possible that the medicalisation of the person with learning disabilities could alter their self-concept in a similar way, although it is also possible that the experience of receiving more care within mainstream health services could positively affect their self-image. However, health checks are only some of the health consultations that people with learning disabilities experience. It is not always easy to distinguish between different types of consultation, and there are often relationships between experiences due to note-taking and communication between health professionals across different consultations. Indeed, a key aspect of health checks is to identify specific health issues and refer the person to specialist services in order to address them. Additionally, the service users will make connections between their various health professional encounters. Consequently, it is necessary to review and explore the experiences of all health consultations in order to understand the service user's role within them, and the effects of these interactions on the service user's self-concept and engagement with health services. Thus, the research aims to uncover where service user and service provider share meanings of the interaction within the health consultation, and where they do not, as well as to highlight those accepted views of role and self that may be shared but not recognised, and may not be helpful to feelings of satisfaction with the consultation (Epstein, Franks, Fiscella, et al., 2005a).

This chapter has identified the right of people with learning disabilities to receive equitable healthcare with that of the general population, but with reasonable adjustments to facilitate access and address their needs in relation to health and communication. The inequalities in healthcare and health outcomes between people with learning disabilities and the general population have been identified, and the development of annual health checks and health facilitation as a response to these issues has been explained. The ethical, psychological and health-related importance of service user satisfaction with, and

evaluation of, health consultations has been established, leading to a need to explore the health consultation experience for a person with learning disabilities from their own perspective, with a particular focus on how they interpret the experience. Therefore, the question addressed by this research study is:

*What is the experience of health consultations for a person with learning disabilities?*

## **Chapter 2: Methodology**

### **Introduction to Methodology**

This chapter explains the choices that were made about how the research question (*The health consultation experience for people with learning disabilities*) could be studied as effectively as possible within the constraints and opportunities of the real world (Robson, 2011). Following a discussion of the epistemological position of this research, the use of a constructivist grounded theory methodology to address the research question will be justified, and the importance of using a symbolic interactionist perspective will be argued. Management of ethical issues related to carrying out research into healthcare for people with learning disabilities will be analysed in relation to the current study, and the consequent effects of ethical guidelines and practical considerations on the study design will be evaluated. The research methods used will be critiqued. Finally, a brief outline of constructivist grounded theory data analysis methods and their use in the current study will be considered.

### **Overview of Epistemological Perspectives**

Doctor-patient consultations have been studied (Campbell et al., 2007) to identify causes of, and barriers to, patient satisfaction (Andén, Andersson, & Rudebeck, 2006; Beach et al., 2006), adherence to treatment (Elwyn et al., 2005) and improved health outcomes (Auerbach et al., 2002). Research methods included restricted questions about satisfaction with communication of information (Kincey et al., 1975); quantitative checklist studies of communication in consultations, personality fit and outcome (Auerbach et al., 2002; Campbell et al., 2007) and person-centredness in consultations (Elwyn et al., 2003); correlations between psychological and physiological variables (Clucas et al., 2011; Kiecolt-Glaser et al., 2002); and interviews with patients after their consultations about their experience and how it affected concordance (Stevenson, Barry, Britten, Barber, & Bradley, 2000). Given the nature of the research question, and the lack of researched knowledge of the interaction between the person with learning disabilities and the healthcare professional within the consultation before this study was commenced in 2008, it was necessary to develop some theory or model of the experience for the service user in this situation in order to develop a body of research that could be investigated and applied to nursing practice. Within the positivist paradigm, model development needs to be based on specific sets of observations, which would narrow the field of enquiry before gathering

data. This could result in missing important insights, particularly in an under-researched field. In addition, falsifiable theories of human interaction are unlikely to be useful because they would need to be very narrow in focus in order to develop a hypothesis that could be measured and not be affected by other variables. Since human behaviour is generally complex and difficult to predict (Ajzen, 2011), the measurement of human experience is problematic, and attempts to do so generally fail to add to our understanding (Briskman, 1972).

Having rejected a positivist approach due to its reductionist nature, its inability to address human experience (Streubert & Carpenter, 2011) and its requirement to frame the research question prior to collecting the data, it was necessary to identify an alternative methodological approach. Positivism is rejected by postmodernist researchers, whose focus of study is purely the meaning for the individual, without reference to any external physical or social reality (Crotty, 1998). This rejection of general truths is based not only on the view that reality is uncertain and changes dependent on place and perspective, but also that other forces, such as power (Foucault) or scientists' belief systems (Kuhn) play a strong role in the dominant view of what is true at any time. Foucault has argued that this interpretation of knowledge by the powerful results in a discourse, existing within institutions and societal structures, where difference from the norm becomes subversive and the person who thinks or behaves differently is labelled as either criminal or mentally ill or sexually abnormal in order to maintain the myth of the dominant "truth" (Appignanesi, 1995; Crotty, 1998; Kuhn, 1970). His stance as a "critical intellectual" (Gutting, 2005, p. 24) is essential in ensuring that the research question itself is not based on a problem of the researcher's own devising, but a questioning of the uncritical acceptance that healthcare, by its nature, is benign. Postmodern subjectivism suggests the impossibility of escaping from an institutional reproduction of anti-humanist practice, tending towards an acceptance of the absence of a coherent reality. However, while important in preventing a blind acceptance of a dominant paradigm of healthcare, a purely subjectivist approach would be of little use in practice development as, without shared meanings or a grounding of experience in reality, it would not be possible to develop relevant theory for application.

It has been argued that critical realism is a "third way" between relativism (where truth is relative to the perspective of the participant or researcher or context) and positivism (where truth is generalisable) (Bergin, Wells, & Owen, 2008). One of the key foundations of critical realism is that there are different domains and levels of reality, which enable researchers to refer all their findings back to one reality at an appropriate level, but

still explore the idiographic experiences of individuals within it. Using this approach, they suggest it is possible to claim a more generalisable explanatory theory from their research than a relativist approach would allow, while not excluding the subjective lived experience. Empiricism, objectivity and falsifiability, the bedrock of the scientific approach (Magee, 1975), would be incorporated into the critical realist epistemology through referring up and down to the levels where their use would be appropriate in order to frame the research within its generalisable context. However, this puts the researcher in the position of deciding the relative validity of different “truths”, and the critical realist theory is assumed to be “the truth” from which criticism of all other theory that disagrees with it follows (Hammersley, 2009). The merit critical realists give to their “truth” lacks the intrinsic falsifiability of the scientific method, yet attempts to retain its claim to generalisability (Cruickshank, 2012). A critical realist approach, where objective truths can be found and potentially falsified, avoids the inability of constructivism “to consider the social world as greater than people’s interpretations of it” (Bergin et al., 2008, p. 172). It also credits its researchers with the neutrality and objectivity that even natural scientists would hesitate to claim. Indeed, Popper himself (who claimed the basis of science to be the falsifiability of its theories) rejected the logical positivist position of observation equating to truth, and accepted that science could only address limited areas of knowledge (Magee, 1975).

Interpretivism holds that different views of reality are dependent on perceptions, attitudes and beliefs held by individuals, meaning that thoughts, feelings and behaviour are complex and not amenable to reduction in terms of laws and cause-and-effect theory (Crotty, 1998). Consequently, a qualitative research methodology, which explores complexity within a specific context, and requires the researcher to be aware of their own assumptions in order to avoid fitting the data to their perspective, was appropriate (Holloway, 2005). A qualitative approach can help professionals to understand the service user experience; it can illuminate the meaning health professionals give to their own work; it is person-centred, rather than process-focused; it explores the reasons underlying people’s behaviour, to inform change (Holloway, 2005); and it is a mainstream methodological approach within healthcare research (Green & Thorogood, 2009). Interpretivist researchers accept that individual studies may appear to conflict, and individual views and perspectives may differ, yet accept that these relative truths are based on an interplay between objects that people experience and their perceptions of them. This is based on the social science constructivist perspective that people construct their own understanding of the world, or reality, through their participation in it (Charmaz, 2006, p.

187). [In this thesis, unless referring to other writers' specific interpretation of approach, the term constructivist has been used to denote the construction of meaning between actors in and on the world, after Lev Vygotsky (Liu & Matthews, 2005)]. This research begins with the view that there is not one objective truth, but that truth is socially constructed out of shared meanings between people. This constructivist epistemology is not the opposite to realism – it is possible to accept that doctors and nurses exist and that interactions happen, but the interpretation of their meaning may be different for the different people involved. The meaning that the health interaction has for the person with learning disabilities may not simply be different to the meaning that it has for the health professional involved, or from the carer who attends the consultation with them. It may also be different to what those involved think it is, or to what theorists in the field suggest it might be. Therefore, grounded theory aims to add new findings to a set of accepted beliefs and find another interpretation, or develop a different model of that social construct (the service user experience of health consultations), to create new theory.

### **Rationale for Use of Constructivist Grounded Theory Methodology**

Constructivist grounded theory uses a symbolic interactionist perspective, in which actors engage with others on the basis of shared meanings expressed in language and behaviour, and modify their views of themselves in the world as a consequence of those experiences (Charon, 2006). This perspective allows the research to explore the meanings of the experience for the individual and build a theoretical understanding of the phenomenon that incorporates the view of the self developed from the interaction, and from previous interactions (see *The role of symbolic interactionism within grounded theory*). Although primarily focused on the service user perspective, grounded theory allows access to multiple data sources (companion explanations, health provider information, audio-recordings of consultations, focus groups and interviews, as well as my own field notes, memos and reflections) for understanding the person's experience of health consultations and their meanings, and to develop a theoretical framework from them to inform future health practice. Grounded theory is useful for developing a theoretical framework to inform practice in areas where there is little existing knowledge, as it is both systematic and flexible in its approach (Charmaz, 2006). Since health checks and health action planning are a relatively new phenomenon in the healthcare experiences of people with learning disabilities, and at the beginning of the study there was little evaluation of the service



user's experiences of health consultations, grounded theory was a useful methodology for developing a model to understand the experience and guide future practice and research.

Strauss and Glaser developed grounded theory (Glaser & Strauss, 1967) when the dominant paradigm in social research was based on the superiority of quantitative methodology (Denzin & Lincoln, 2011). The success of the scientific method, with its emphasis on identifying the boundaries of knowledge, devising experiments to test the "best theory" and adapting it in response to data (Magee, 1975), had become culturally dominant, despite some criticism. Grounded theory was originally proposed as an empirical method of systematic social inquiry that could generate middle-range, testable theory from observation (Glaser & Strauss, 1967). As sociologists, they were responding to criticisms that sociology included some "dreamed-up, speculative or logically deduced theory" that was not grounded in data (Glaser & Strauss, 1967, p. 5). Grounded theory, purposefully developed in relation to a question of interest, would therefore be usable in the real world, giving explanation of and predictability to situations in practice. It used an inductive approach, where qualitative data were collected and analysed to develop a framework for understanding a situation. This theoretical framework had to contain testable categories and hypotheses, and these categories had to fit the data – "be readily (not forcibly) applicable to and indicated by the data under study" – and work – "be meaningfully relevant to and be able to explain the behavior under study" (Glaser & Strauss, 1967, p. 3). The focus was on using a rigorous approach to make the method transparent and replicable (Glaser & Strauss, 1967).

Two key concepts were formulated in this classical grounded theory. The first was constant comparative analysis of data and categories with each other throughout the data collection and analysis process, to ensure that new theory was developed to fit the data, rather than existing theoretical concepts being forced onto the data. The second was the concept of data saturation, occurring once new data cease to add new categories or generate new theoretical understanding related to the experience (Glaser & Strauss, 1967). This version of grounded theory was seen as an attempt to compete with quantitative research in terms of rigour, replicability and objectivity (Charmaz, 2006; Denzin & Lincoln, 2003). However, Kuhn's view that science resisted conflicting findings until generational change allowed paradigm shift following overwhelming evidence against the status quo (Kuhn, 1970), and Feyerabend's contention that scientific theory is culturally dependent and rarely tested for falsifiability, were moving scientific research to a post-positivist world, where all scientific knowledge was dependent on current models or constructs, and there

was no such thing as one absolute truth. The role of the researcher was now to question findings, conclusions and accepted theory, and the scientific view became a theoretical position, rather than an absolute fact (Crotty, 1998). The main criticism of the original grounded theory was that it viewed data as objective and separate to the researcher's perspective and understanding while collecting and analysing it, when opinion and narrative, as well as the researcher's understanding of them, must relate to the individuals involved in the research, and their interactions with the researcher (Mills, Bonner, & Francis, 2006). Corbin addressed this criticism, identifying the symbolic interactionist foundation of grounded theory and stating that her views on grounded theory had changed, and that it could be used within a constructivist perspective. Consequently, she emphasised the importance of the researcher making their thought processes and experiences throughout the research process explicit in grounded theory methodology (Corbin & Strauss, 2008).

Charmaz (2006) rejected the positivist leanings, particularly of Glaser, and focuses more on the fieldwork focus and empathic, symbolic interactionist "Chicago School" research tradition of Strauss. She also identified the importance of acknowledging the researcher's role in constructing theory through their interactions with the participants' understanding of the experience, to make explicit the symbolic interactionist stance that the analysis has gone through at least two interpretations: the understanding the participant takes from the experience under scrutiny, which is then understood by the researcher and re-framed within the context of their understanding of the rest of the data gathered from other participants and their own analytical memos. These memos are meant to capture the development of the researcher's insights into the analysis, but are analysed as data in themselves. The original grounded theory approach contended that, by following a systematic, rigorous and replicable method, the findings could be seen to be objective (Hildenbrand, 2007). By contrast, when applying grounded theory from a constructivist perspective, if the researcher's role in the process is not acknowledged and understood, the findings are credited with much greater objectivity than they actually possess. The process, and the researcher's involvement in it, must be transparent, verifiable and rigorous, in order for others to assess the credibility, originality, resonance, usefulness and ultimate value of the research (Charmaz, 2006), so the theoretical perspective and study designs used are clearly explained in this chapter, including the centrality of the symbolic interactionist perspective within this thesis.

Constructivism allows the exploration of the effects of unspoken communication in health practice (Carr, 2004). Constructivist grounded theory is also useful in understanding the experiences and needs of people with learning disabilities related to health consultations, because it does not assume knowledge and allows the researcher to explore the situation that exists, rather than framing the question on the basis of health professional or social science theory. It would be emancipatory and therefore desirable to use a participatory and co-constructed understanding of the lived experience of health consultations with people with learning disabilities (Lincoln, Lynham, & Guba, 2011), and this was seriously considered. However, in practical terms, I did not have any personal contacts with GP services and, although community learning disability services gave R&D permission, again I was unable to gain personal support from any gatekeepers. In addition, I had to gain approval both in terms of the viability of the study as a PhD, and ethically. Without existing relationships with a group of service users, it was not possible to develop participatory research within the existing time constraint. Nonetheless, Kant's philosophical tenet that people must be treated as of value and as an end in themselves, and not a means to an end (Kant, 2002) [originally published in 1785] was central to the research at all times, and the quality of the interaction with participants was prioritised in order to minimise risk of discomfort and maximise benefits to the person (Bridges, 2001). The most realistic aim was to understand and reconstruct the service users' views of their experiences in order to develop theory to inform practice using grounded theory as a methodological approach that is "visible, comprehensible and replicable" (Bryant & Charmaz, 2010, p. 33).

### **The Role of Symbolic Interactionism within Grounded Theory**

The assumptions of constructivist grounded theory are based on a symbolic interactionist perspective (Bluff, 2005), a view that the interpretation and meaning of symbols in communication is learned through socialisation. Symbols are social objects that are learned through social experience, which are used to communicate with each other and with ourselves. Unintentional communication, such as body language, still symbolises a perception of the other and it will still affect the person's understanding of a social interaction. Symbols such as written and spoken language, processes and procedures, are all ways of communicating something about a person within a social situation, and will have an effect on their self-concept, particularly within that situation. This shared meaning provides some predictability to and understanding of the behaviour of others, and allows us

to adapt our behaviour in different social circumstances. The constant reinterpretation of our own and others' behaviour and meanings leads to a view of our self (self-concept) that is based on our interpretation of other people's behaviour towards us. This self-concept is actively constructed by the individual, but is also dependent on social context. Consequently, to understand the individual, the social processes and context of interactions need to be explored and made explicit in the research process (Bluff, 2005).

Symbolic interactionism arises from the work of the social psychologist George Herbert Mead, who worked within both psychology and sociology, and is placed within sociological social psychology (Charon, 2006). Mead's discussion of the differentiation between the experiencing, self-as-subject "I" and the self-as-object "me" (an internalised view of the self, based on the views and attitudes of other people) derived from the earlier work of his colleague, William James (Schellenberg, 1978). James was a philosopher and psychologist, who identified different influences on the development of the self, including social influences (James, 1890). James identified that the social self was not a singular concept, but that an individual holds multiple views of themselves as seen by others, dependent on context. Mead focused on how the individual's perceptions of others' views of them built into a sense of the generalised other, and how that informed their self-concept. C.H. Cooley added the concept of the looking-glass self to Mead's theory of social interactionism. He suggested that an individual incorporates the views of others in a three-stage process. Firstly, they imagine what the other person thinks and feels about them; then they imagine how that person will judge them; and finally, they will assimilate those conclusions into their own self-concept, so that their assessment of how others see and value them become part of their own self-concept and self-esteem (Roth, 1990). Goffman (1959) developed the symbolic interactionist perspective into the dramaturgical model of the self, where the self as performer (the "I") and the self as audience (the "me") are joined by the self as the character (or role) performed. Thus, the actor attempts to live up to the role, adopting it as a mask to disguise the private person. James identified the importance of the difference between a person's perception of the self, and their ideal self (James, 1890), a cornerstone of Carl Rogers' theory of the self, where feeling able to respect oneself, through the acceptance of others, and attainable ideals, is essential to mental well-being (Rogers, 1961).

Goffman's theory is especially relevant in health consultations, where the service user may feel the need to present themselves as credible, in order to achieve the healthcare investigations and interventions that they need, particularly if they have any

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discrediting stigmas or unexplainable symptoms (Werner & Malterud, 2003). The need for presenting the self as creditable, combined with having to access health care via the “gatekeeper” and thus assume the “sick role” (Parsons, 1951) creates a deviance from the norm. This then attracts a label if the person is unable to resume health, as would be the case with long-term illness or disability. Fundamental to the relationship between the service user and the gatekeeper, or health professional, is the subjective interpretation of reality. This reality is negotiated between people within the encounter, informed by previous related experiences that imbue symbols with meaning (Blumer, 1969). In that sense, health consultations are concentrated, time-limited episodes, in which service users have a defining opportunity to develop an understanding with the health professional. In order for the service user to maintain a positive self-concept within the encounter, they must negotiate an agreement with the health professional about both their physical needs and about who they are. These understandings inform their future actions (Blumer, 1969), resulting in a greater or lesser degree of agency in their own health and future health encounters.

Charmaz (1983) argues that one of the factors involved in the loss of self-esteem and self-identity in people with long-term illness is the way they are seen and treated by health professionals. She suggests that, particularly where people are more isolated from society, the interaction with the physician assumes greater importance in the co-construction of the self-concept, and concluded that “When ill persons receive positive reflections of self in interaction and take them as credible and real, they are more apt to regard themselves positively. But when demeaned and discredited by those to whom they attach significance — even during the briefest of interactions — then maintaining a positive self-image becomes problematic.” (Charmaz, 1983, p. 181). People with learning disabilities are labelled as such within the healthcare system, and that label has been shown by diagnostic overshadowing (Michael & Richardson, 2008) to have an important meaning for health professionals. The importance of the label of learning disability in health, being so strong that it can alter the usual algorithms of assessment, tests, diagnosis and treatment, must be communicated to service users and their carers, affecting their self-concept and self-esteem, at least within the health encounter. Therefore, the focus of the research method will be to identify, explore and understand shared meanings within the health consultation from the interpreted reality of the service user with learning disabilities, and establish how that, in turn, relates to their self-concept, and therefore identity, and how it might affect healthcare and health outcomes. Identity is the way in which someone defines themselves,

locates themselves in relation to other people, and differentiates self from other. This is a subjective view, based on how people wish to see themselves, as well as how they perceive others see them (Charmaz, 2006). Thus, an important outcome of using symbolic interactionism as the theoretical perspective underpinning this grounded theory study will be to understand the effects that health consultations have on the identity of the participants.

The use of a symbolic interactionist, constructivist approach to grounded theory also highlights the subjectivity of the analysis, particularly because the participants' understandings of the experience are then "understood" from the perspective of the researcher. This demands explicit examination of my role, as researcher, within the research process, including explication of the decision-making process through the design, data collection, data analysis and discussion of findings. This reflexivity is even more important than delaying the literature review until after the generation of categories (McGhee, Marland, & Atkinson, 2007), because it is only by making held views explicit that the researcher and others are able to question them, and assess their influence on the findings. My view of the world is influenced by being both an adult and learning disabilities field nurse, as well as on having been a service user whose own credibility came into question before diagnosis of a serious illness. These multiple perspectives have increased my sensitivity to and engagement with the worldviews of participants in this study (McCreaddie & Payne, 2010). In particular, my experience and knowledge as learning disabilities nurse has given me greater understanding of the context of the lives of people with learning disabilities, making it easier for me to empathise with participants. This will have had an impact on the data generated and its analysis, as this positive emotional engagement with the participants promoted a sense of trust and openness within the research encounter, enhancing the sharing of relational power within the research process (Hall & Callery, 2001). It also gave me a great sense of responsibility to respect and value their identities throughout the study. Thus, the participant voice is represented to underpin all the categories, and the themes are related, not just to their experience, but how it affects their self-concept and sense of identity. In view of these methodological decisions, the final research question became:

*The health consultation experience for a person with learning disabilities: A constructivist grounded theory study based on symbolic interactionism*

**I told the participants that I was a learning disabilities and hospital nurse, who used to work in accident and emergency, but now taught nurses. This meant I wanted to find out from them what their experiences of health consultations were like, and what they wanted to improve, so that I could make sure that student nurses learned the best way to nurse them. There were differences in how open the participants were, depending on the setting and who was with the service user when I interviewed them. Where there was a health facilitator present, or I was introduced by the health facilitator, much of the focus was on the improvements that had been made in their care, although this highlighted the long-term effects of their negative experiences in the past, and participants still revealed information that was partly unknown to the health facilitator. Where I interviewed people via the self-advocacy facilitator or just through introduction by social services carers, participants were generally more openly critical of their health experiences, despite some evidence of fear of disclosure (discussed in *The interview experience*). This highlighted the importance of interviewing people in different settings, and via different routes, in an effort to prevent a single influence from dominating the findings. This study will be evaluated in *Reflections on methodology* using criteria developed by Charmaz (2006) of credibility, originality and usefulness.**

**Ethical Issues**

The Mental Capacity Act (2005) regulates issues related to consent to research for people with learning disabilities. Someone with learning disabilities should not be assumed to lack the mental capacity to choose to take part in this research. The researcher checked that the service user knew what the research is for, what it involves, and that they could refuse to take part without any ill-effects to themselves at any time, and that they knew what the risks and benefits were in order to make a decision. The participant information sheet (see Appendix 3) was used as the basis for this explanation. This was written in simple language with appropriate illustrations to support it, and a copy was given to the potential participant to take home with them. They were advised to discuss it with significant others for advice. In order to ensure that consent was clearly explained and understood, it was explained in the presence of a relative, unpaid carer, friend or advocate, who was asked to sign to witness that the consent of the participant was given freely and with understanding. The consent form explicitly asked for consent to audio-record the interviews and consultation, and this was reinforced in the interview by drawing attention to the red light when recording commenced and explaining that recording had started.

Some people would be unable to take part if they were unable to understand the research, or unable to communicate their needs at all. This is an unfortunate, but unavoidable, limitation of the research and may limit its generalisability. However, one of the people interviewed in the focus groups, who also attended the member check, used a language board and, although her verbal contributions could not be recorded, she wanted to be involved in the research, and attended the member check meeting with her carer, in order to do so. Several of the participants had quite limited verbal ability, but were still able to contribute and express their views. I made it very clear (both in writing and verbally) that I was not present to intervene in the health process in any way and that the participant could withdraw from the research without it affecting their care in any way.

Evaluation of any service is essential for quality assurance purposes. The lack of research into primary healthcare for people with learning disabilities means it is difficult to apply clinical governance to the service. This is compounded by the care for people with learning disabilities generally not being included in other audits or research. This is because of ethical issues related to being vulnerable adults, or for practical data collection reasons. Given the importance of communication within the healthcare consultation, particularly where barriers to communication may exist, it was necessary to understand what issues might be important from the service user's perspective. Initially, it was thought that this could be explored through listening to audio-recordings of the consultation, and comparing the agendas discussed with the person's stated agendas before the consultation and the person's view of the health outcomes after the consultation. The recorded consultations could then be explored, to identify whether those issues were communicated within the consultation, and how this may affect health and the health consultation experience for the service user. This would also allow for an analysis of which strategies and approaches used by the practitioner were more or less successful. People with learning disabilities have as much right as any other group of service users to have a say in the evaluation of their own service, and this study would enable the experience of the service user and its effect on health outcomes to be evaluated from their own perspective. However, this approach was modified quite early in the research process, to one in which focus groups and interviews were used to explore participants' health consultation experiences, without audio-recording consultations (see *Study design* and *Data collection methods* for discussion). This resulted in understanding the experience more straightforwardly from the service user perspective.



Healthcare consultations for people with learning disabilities are difficult to evaluate for several reasons. Firstly, it is often difficult for people with learning disabilities to articulate their thoughts and feelings about an experience. Secondly, they may not know what the experience should be like or have much with which to compare it. It was thought important, therefore, to find out what their aims, fears and expectations really are by asking about them before and after the consultation. Additionally, to have some independent knowledge of the experience, the consultation has to be open to scrutiny. This required both pre-consultation and post-consultation interviews with the service user to compare their agendas and consultation outcomes. Dates were to be arranged between the practice and the researcher to ensure that the researcher interviewed the participant before the Direct Enhanced Service (DES) appointment. In view of the potential risks of being a lone worker, a risk assessment would be carried out (with the aid of practice staff) to decide whether the interviews would be carried out in the participant's home or within the practice.

Another potential burden for the participants was that their health consultation would be recorded. Audio-recording of patient consultations is routinely used by GPs as a learning tool and as a means to evaluate their consultations (Rushmer et al., 2011). While it might potentially affect the behaviour of people within the consultation, it is less obtrusive than video recording or the presence of a note-taker, and unlikely to have a negative effect on the consultation. A note-taking observer, no matter how well intentioned, might alter the dynamic of the consultation. It was decided, therefore, that audio-recording would be the least intrusive and most accurate way of collecting the most authentic data. This design was burdensome, in terms of time and intrusion for the participant, and difficult to fit into the running of the GP practice. However, this was necessary to uncover aspects of the consultation that are important to the care and experience of someone with learning disabilities. For the participant, discussing and articulating their health agendas might be a useful practice prior to the consultation. The knowledge that their thoughts are important for evaluation might have enhanced their self-efficacy. Despite the effort and potential intrusion, with their consultations being under scrutiny by all involved, care governance and quality assurance were likely to be high. The intention was that GPs could use their involvement in this study to evidence service-user evaluations of the DES, as part of their GP contract.

## ***Study Design***

### *Study 1*

The first study was influenced by a study design that had previously been used to answer a similar question, that is, a detailed analysis of people's agendas for health consultations, how well they were met, and relevant factors within the consultation that affected those outcomes (Barry et al., 2000). This study was described as using mixed methods, within a postmodern, social constructionist paradigm, to triangulate findings and enrich understanding of health consultations by observation of what people do, as well as what the consultation means to them (Barry, 2002). However, it was based on a medical discourse approach (see *Expressing agendas* for detailed discussion of this epistemological approach and its assumptions), which means that the researcher has to compare meanings and arrive at their own understanding of events. This approach was inconsistent with a symbolic interactionist perspective, where the goal is to understand how the process of health consultations affects the participant's self-concept within that social process. Nonetheless, in the initial phase of the current study, this method did provide an opportunity to see how the GP practice setting affected the participant compared with being interviewed at home.

The original study was to observe the qualitative ways in which people's health consultation agendas were met, or were hindered, within the GP consultation (Barry et al., 2000). Patients were interviewed in the GP practice about their health concerns, fears and desired outcomes from the consultation, prior to seeing their doctor. The consultation was then audio-recorded, and the person was interviewed a few days later to ask them how well they felt their agendas had been met within the consultation. The consultations were analysed in relation to these interviews to identify what happened within consultations and how that affected outcomes, including adherence. Using direct comparison between people's expressed views in interviews and those in the consultations, it was found that people often did not express their agendas within the more biomedical, diagnostic approach of a GP consultation, sometimes with serious effects on the effectiveness of the health consultations on their health outcomes (Barry et al., 2000). Since the current study was aiming to answer a similar research question, only with everyday GP consultations, it seemed to offer an appropriate study design, which focused on the interactions between the service user and the healthcare practitioner. However, with hindsight, it was a conflicting methodology to use within a grounded theory approach, since the aim of discourse analysis is to explore the use of language to achieve personal, social and political

goals, while grounded theory is used to develop an explanatory model of basic social processes in context, and understand their effect on the person's self-concept, in order to inform future practice (Starks & Brown Trinidad, 2007). This was corrected after collecting data from one participant (partly due to difficulties in accessing health consultations in practice) to a design where service users were simply asked, in group, paired and individual interviews, about their health consultation experiences (see *Ethical issues, real world research and study modifications*).

### ***Ethical Issues Revisited, Real World Research and Study Modifications***

Initial written attempts to contact GP practices in the local Trust offering the DES for people with learning disabilities, to discuss the possibility of the research, were unfruitful. Through a notice on the GP consortium agenda, one GP made e-mail contact, as they were interested in evaluating the new DES they provided for people with learning disabilities. Since the chances of someone with learning disabilities attending any one GP surgery is small, the study needed to focus on people accessing the DES, which meant their agendas were likely to be less clear than if they had a specific problem requiring assessment and possible intervention. Following discussion with the GP and advanced nurse practitioner, it was identified that the person (and usually their carer) would need to be approached beforehand to ask if they would be willing to meet with the researcher, to discuss the research and to take part if they wanted to. This pre-planning had implications for the recruitment of participants and the relevance of the discussion of agendas. The attempt was made to contact the local partnership boards to discuss the research proposal with them, in order to gain a service user perspective, but access was not gained. After discussion with a retired scientist and ex-Justice of the Peace whose adult son had learning disabilities, who felt that the research was justified and appropriate, university ethics approval was sought. This was given, following minor amendments to the use of language in the participant information sheet.

In the process of obtaining ethical approval through the integrated research application system (IRAS) (see Appendix 2, approval letter dated 25<sup>th</sup> January 2010) – the single system for applying for permissions and approvals for health and social care/community care research in the UK – some modifications had to be made to the study design that formed the basis for this research (Barry et al., 2000). Regulations covering patient confidentiality meant that the service user had to be contacted via their GP practice, and could not be contacted directly by the researcher. This meant that the

researcher could be perceived as being part of the social organisation of the experience, which could influence the perceptions of the service user and carer about the purpose of the research and the aims of the researcher. More importantly, though, it built a barrier into the process whereby the practitioner identified which participants were included in the study. This had implications for possible bias in the sample of participants. The key stages in the final study protocol are outlined in Table 4.

<b>Table 4: Protocol - study design 1</b>	
1	Letter sent by GP practice to potential participant asking if they would be willing to have their contact details given to a researcher who wants to find out about their experience of healthcare.
2	Follow-up telephone call by practice administrator or nurse clinician, if no response, to ask the same question (Permission can only be given by potential participant).
3	Meeting with potential participant and their representative (unpaid carer, guardian, relative, advocate) to explain the research, and ask for informed, witnessed consent. Main researcher (HMC) to gain consent, either in the practice or at their home, witnessed by their representative dependent on a risk assessment.
4	Discussion of the service user's health concerns, expectations and aims of the consultation audio-recorded for transcription. Carried out by main researcher (HMC) in GP practice or participant's home, prior to consultation.
5	Audio-taping of consultation between service user and GP (or nurse clinician). Consultation digitally audio-recorded by GP or nurse (previously set up by HMC).
6	Post-consultation interview (audio-recorded) to find out the service user's perceptions of the outcomes from the consultation audio-recorded for transcription. Carried out by researcher (HMC) at service user's home or in practice, dependent on risk assessment.
7	Feedback to the service user of any findings and outcomes from the research and discussion of interpretations in the form of a meeting for participants (audio-recorded).

This design meant that, as well as the audio-recording of the consultation to identify what actually happens, the participant was interviewed twice. Firstly, before the consultation, in order to identify their agendas (their aims, their fears, outcomes which they may or may not want, any particular concerns); and secondly, after the consultation, to see if it met their needs (helped them to understand or manage their health; get investigations or interventions for their health; validated their concerns or questions). These were also audio-recorded for accuracy and research audit purposes.

## Data Collection Methods

Table 5: Agenda category - Basis for interview schedule	
	(Barry et al., 2000)
Symptoms	
Prescription request	
Previous self-treatment	
Request for diagnosis	
Theories about diagnosis	
Reporting of, or discussion about, side-effects	
Worries about diagnosis or prognosis	
Not wanting a prescription	
Social control	

Initially semi-structured interviews were used to explore the agendas of the participant before the audio-recorded consultation and, a few days later, how well the person felt their agendas had been met. The interview schedules were derived from those areas identified in the study by Barry et al. (2000) as the types of agenda that people had before they saw their GP (see Table 5).

Pictures were also used to aid understanding and help participants to identify their agendas (see Appendix 5b). The focus of these questions was on the viewpoint, expectations and satisfaction of the participant with the experience (see Appendices 5a, and 6 for interview schedules). This emphasis on viewpoint and feelings rather than facts and knowledge reduced the potential for the participant to feel there was a right or wrong answer, which could be particularly stressful for someone with learning disabilities. The use of semi-structured interviews has several advantages. Firstly, it is flexible and adaptable, allowing the opportunity for the service user to introduce their own concerns. Secondly, the language can be adapted to the communication needs of the service user and, because it is face-to-face, augmented language skills, such as language boards and Makaton, can be used (at a rudimentary, but helpful, level in this case). Although these were not used a lot,

they were occasionally helpful in correcting misunderstood verbal language, or in adding emotion to it. Collaboration in using augmented communication also demonstrated a willingness to engage with the participants that promoted good relationships with them. The use of non-verbal cues and hesitation sometimes indicated where there was a sensitive issue, or an area of concern that could then be followed-up. This would not be possible with surveys or even structured interviews (Robson, 2011). Another advantage of semi-structured interviews, compared with open narrative or unstructured interviews, is that it allows review bodies, especially ethics committees, the opportunity to scrutinise the questioning approach and areas of interest of the interview. This is particularly important in research with people with learning disabilities, in view of their potential vulnerability to feeling interrogated or confused (see *Explanations and understanding in health consultations* for a more detailed discussion of potential issues of suggestibility, acquiescence and confabulation).

However, face-to-face interviews are time-consuming for both researcher and participant (Robson, 2011), and the complexity of the social situation (a triadic interview, effectively) for the first pre-consultation interview caused an unanticipated difficulty. The time it took to ensure that consent was informed, and the service user understood the research was greater than had been allowed for in the GP practice booking system, despite my advice to the contrary, which meant that the pre-consultation interview had to be curtailed, and the delay in the service user attending their health check appointment was disruptive to the healthcare provider, service user and carer. The interviews were audio-recorded for accuracy, but as well as explanation, attention was drawn to the red light, so that participants were aware that they were being recorded.

From the first interview, an important pragmatic decision was made. Carers often intervened to aid communication for the person with learning disabilities and were present throughout the consent process to ensure transparency. Consequently, they sometimes stayed for the interview and often became involved in the interview itself. While this study was supposed to be an opportunity to hear the voice of the service user, and the service user was encouraged to respond to questions, the decision was made that carers would not be asked to leave, and their contributions would be treated as data. There were two reasons for this decision. Firstly, because this was a more naturalistic approach and was likely to yield data about how the presence of the carer affected the health consultation. Secondly, because excluding them might have created a barrier to trust that could have affected the service user. Potentially, this could weaken the claim of this study to represent

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the views and experiences of service users (Marriott & Williams, 2012), but the data collected and analysed was almost exclusively in the voice of the participant, and any other person's contribution is made transparent and is either qualified, commented upon, used to provide context or excluded from the analysis. Furthermore, although the initial study design was adapted from a study of service users from the general population, the later study designs were adapted to the preferences of service users and incorporated methods and questions raised by service user focus groups.

Due to the complexities of planning and designing this study to be relevant to current local healthcare practice, to conform to ethical protection for vulnerable adults and to gain access to the highly confidential GP consultation, it took over a year to design and gain approval for this study. Unfortunately, additional safeguards including a research passport and an enhanced criminal records bureau (CRB) check could only be gained after this process was completed. This resulted in being unable to capture data from more than one service user from the GP practice accessed for that financial year. Despite the difficulty of that situation, this phase of the research achieved four things. Firstly, it provided some insight into the annual health check proved by the DES, even though it was only one example. Secondly, it provided experience of using the interview tool. Thirdly, it allowed insight into the role of the carer within the consultation and interview. Fourthly, on interviewing the service user at home, it highlighted the difference in their demeanour away from the clinical environment. From being anxious and worried about what to say and how to say it, the service user and carer were more relaxed and open, and a genuine connection was made with them. It highlighted the poor fit between the original data collection method and the aim of hearing the voice of the service user.

Following this interview, it transpired that the required numbers of service users were seen in a block at the GP practice to achieve the annual health check target, and there would not be any more DES appointments until late in the following financial year. The ethical approval required that the 22 GPs in the local community trust who offered the DES were invited (in writing) to take part, but four declined and the rest did not respond. Consequently, not only was there a self-selecting service that pre-selected participants, but, even with full ethics approval, the overwhelming majority of GP practices did not support the research. Patient confidentiality and the protection of vulnerable adults, as well as financial constraints (in that their time is valuable), mean that GP practices have a very high barrier against external evaluation of the service they provide to service users with learning disabilities. At this point, it was decided that since access could not be gained to primary

care consultations, it would be necessary to find a way of accessing service users' views on their consultation experiences through another route.

### *Study 2*

In the second study design, the data collection was completely focused on the service user's perception of their health consultation experiences. Rather than seeing that as an inferior design, however, it made more sense within a symbolic interactionist perspective. It was a distilled version of participants' perceptions of health consultations and their self-concept in them, and focused on their perspective. This time, contact was made with the local social services day service provision for people with learning disabilities, via an academic colleague who provided an introduction to the manager. The manager then e-mailed all the staff to ask if anyone could help with the research. The self-advocacy group facilitator, who worked for a charity that was commissioned by social services to provide this service, responded. The self-advocacy groups had been working on issues around their healthcare, and the facilitator felt that this research fitted into their areas of interest. Following discussion, it was agreed that, once ethical permission (see Appendix 7 for ethical permission to this substantial amendment, dated 7<sup>th</sup> February 2011), CRB checks and access permissions had been given, it would be possible to talk to the two local advocacy groups about the research and ask if any of the members would be interested in taking part. As a courtesy, and to ensure transparency, I presented an outline of my research question, methods and aims to a carer/parent group meeting and, despite initial scepticism about research achieving change, summed up in the words of one parent: *"We've been fighting for years to get decent healthcare"*, the group were highly supportive of the project.

Following this, I attended already-occurring service user groups known to the self-advocacy facilitator. Some were closely related to social services day services facilities, while one group was independent and met in a parish hall. The groups covered a wide area, so this research was not evaluating one service, but exploring issues across a number of different service provider areas. After explaining the research and what it was for, I asked service users if they were interested in being involved. After that, I attended the groups on a weekly basis for a few weeks and service users who were interested in being involved opted in to be interviewed. Sometimes, this could be a group of up to eight participants, but sometimes it was as few as two. Some carers told other service users about the research, who then requested to be involved, so I travelled to their day centres on request to carry out one-to-one interviews. Consequently, a purposive, snowballing sampling



technique, developed from the original naturally occurring group, was used. The advantage of focus groups is that they can provide support for less confident participants, legitimising their views, and allowing issues to be raised and discussed, providing differing viewpoints that might not be discussed in one-to-one interviews. They are also a relatively convenient and efficient way of collecting data. The focus group also reduces the response burden when some people might find it difficult to follow interview questions easily, but can gain an impression of the subject from the conversation. Problematically, it can make it difficult for some voices to be heard, and there are issues of confidentiality in a group situation that can prevent openness (Robson, 2011). The focus group had already discussed health experiences, which gave them some confidence in discussing the issues. However, it was notable that there were more men than women in the focus group, and that they generally contributed more than the women. This led to the adoption of paired or single interviews with women, to encourage their contribution. Demographic information was not collected, but participants covered a wide range of ages from approximately late twenties to late seventies. People had different levels of cognitive ability and different living situations, varying from independent living to full residential care. Some were supported by relatives, some by carers and some contributed independently.

### *Study 3*

Once all interested parties had contributed to the second study, it was clear that more data were needed from women with learning disabilities and people who had a dual diagnosis of learning disability and psychiatric disorder, because related codes had been identified, but there were insufficient data for saturation to have occurred. Consequently, I approached a health facilitator and asked if he would help me to recruit people who might be able to contribute to these categories. This was agreed, so a further ethical amendment was sought and agreed (see Appendix 8). These five participants were all interviewed individually, sometimes with the health facilitator in attendance, to provide reassurance to the participant and to their carers that they were in a safe situation. Throughout the data collection process, field notes and reflections were kept to identify issues as they arose, which have been used in this chapter and in *Reflections on methodology* to allow understanding of the context and process of the research, and inform its conclusions. Although grounded theory was originally based on field notes allowing a fluid analysis of the key social processes that would promote flexible theoretical sampling to pursue the questions that arose from the data (Glaser & Strauss, 1967), this study was audio-recorded for accuracy, and due to working on the research part-time and finding accurate

transcription time-consuming, the analysis was not contemporaneous in the first part of the study. Another reason why theoretical sampling was not as flexible was because the focus groups had engaged in the research, so they were self-selecting and once they had been approached, anyone who wanted to take part had to be given the opportunity. Consequently, the third part of the study was aimed at addressing those questions raised where data saturation had not been possible.

## **The Data Analysis Process**

While some of the data analysis processes used were first introduced by Glaser and Strauss (1965), the constructivist analysis outlined by Charmaz (2006) was used in the current research. A key aspect of grounded theory is constant comparative analysis. The process of analysis begins with the researcher coding the data into as many categories as possible, generating new categories or fitting data into existing categories. As part of this process, the researcher should compare each newly categorised incident with previous incidents noted in the same category, promoting the development of a set of properties that can be applied to each category and allowing cross-checking of ideas to facilitate the next stage of integration of categories and their properties. Following on from this, the researcher needs to reduce the number of categories to eliminate duplication and overlap, and begin to formulate theoretical explanations for the remaining categories, identifying the limits of generalisability of the theory. Once new data cease to add new categories or generate new theoretical understanding related to the experience, the body of data has become saturated and the researcher should bring together the memos from the analysis to identify themes to write into a theory of the experience studied. The comparison continues throughout the process and is intended to reduce the potential for fitting the data into existing ideas, rather than creating new theory from the data (Glaser & Strauss, 1967).

Clearly, Charmaz's (2006) constructivist approach means that the categories do not simply "emerge from the data" (Glaser & Strauss, 1967, p. 36), and even in the original version of the theory (Glaser & Strauss, 1967) the emphasis was on the role of the researcher in generating conceptual categories to explain phenomena. Hence the need for "sensitive insights" (Glaser & Strauss, 1967, p. 251), based on both personal experience and theoretical knowledge. They emphasise that, while the exhaustive pursuit of all that is known about a phenomenon can create a barrier to understanding the data, it is the job of the researcher to "line up what one takes as theoretically possible or probable with what one is finding out in the field" (Glaser & Strauss, 1967, p. 253). The first stage of the analysis

is to produce as many categories as possible from the data, preferably throughout the data collection period. Unfortunately, it was not possible to analyse data contemporaneously, due to competing demands on the researcher's time and the difficulty in transcribing and interpreting the data. In addition, the naturalistic setting of the service user advocacy group meant that the discussion developed according to the people who were available and wished to attend on those days. However, where specific issues arose, for example, identification of difficulties that female service users had in discussing their experiences in mixed-gender focus groups, and when it was found that service users found it difficult to discuss feelings of embarrassment, or issues related to sexual health or psychiatric illness, further interviews were carried out to refine the categories and pursue data saturation.

In data collection, potential issues of relevance to theory were pursued where possible, although this was difficult, particularly within focus groups, as other participants sometimes felt bored or ignored. So, issues related to dissatisfaction with consultations or feelings of embarrassment were generally raised in one-to-one or paired interviews. The initial focus groups raised some categories, particularly related to access and continuity of care, and some aspects of relationships with health professionals, which were then discussed in more depth in the one-to-one and paired interviews. The focus groups stimulated interest in the research, and allowed participants and their carers to gain confidence in the research experience and the researcher, creating a number of opportunities for members of the focus group, or people who shared the same services or were known to service providers, to make contact with me so that they could discuss their health consultations. Finally, when the first wave of analysis was completed, and there were still outstanding questions around past experiences of health consultations, sexual health, psychosocial health/mental illness and gender differences, I made contact with learning disabilities health co-ordinator and a practice nurse, in a different geographical area, who arranged a further five individual interviews. These were with service users who had experienced using mental health services and/or were female, as these categories had been identified through the data collection period but needed saturation to enrich the developing theory through elaboration and qualification. Again, this meant that the choice of participants was influenced by health professionals, which must be accepted as a limitation of the study, but the participants all fulfilled the requirements of the study and were approached via the health facilitator according to my stated criteria. Due to the tension between not wanting to direct participants' responses and participants finding it difficult to understand non-directive questions, data saturation was not always possible,

given the limited time and personnel resources, as well as the difficulty of gaining extensive data from the participants involved, and this restricted theoretical sampling is a limitation of the research.

Throughout the data collection process, memos were written to conceptualise the data and used to formulate theory. Although some of the codes discussed in these memos were not always used in the final analysis, the process of reorganising the data to find a coherent picture of the health consultation from the service user's perspective was necessary to find the "best fit" between data and final thesis. This process was closely supervised in order to ensure the theory was supported by the data. In particular, the initial generation of categories from the earlier interviews was cross-checked and discussed in order to explicate the theory. Additionally, the early final analysis was presented to as many of the original participants as possible, and facilitated group discussions were held to check the resonance of the findings (see *Member checks*).

This initial coding and development of some focused coding was carried out using a constant comparative process, where every time a new code was identified it was searched for in the previous data. Comparisons were made with similar experiences, or opposite outcomes, to identify where participants were identifying either a common theme or a specifically different experience that added insight into the consultation experience for people with learning disabilities. The development of focused coding sometimes occurred during this process, as a category identified from the participants' experiences forced connections with theory, and the relationship was explored in memos. For example, I observed that a participant felt less anxious about his health when he accepted that it was in the hands of expert health professionals, but that this also gave him a reduced sense of control both within the consultation and with regard to his health behaviours and outcomes. Hence, I developed a dual label code of ?No control/self-efficacy, so that instances of feelings of control and feelings/behaviours related to self-efficacy could be captured together and discussed in relation to existing theory. However, although it contributed to the overall analysis, this code was not included as a discrete category in the final model, for two reasons. Firstly because it was subsumed within other categories, such as involvement/inclusion in the consultation, relationship with health professional, and strategies to reduce anxiety; but also because, through inexperience in using grounded theory, this was one of my earlier codes that was partially derived from my existing theoretical perspective. At the end of this coding process, 71 categories had been

identified. Some were clearly related to others in clusters, and there were some that recurred and seemed significant to participants' understanding of the health consultation.

Initially, the categories were simply organised by the order in which they were identified. 29 out of the original 71 codes were not used in the final analysis, although several were incorporated into other categories. This was partly because the dropped codes were covered in other discussions, and partly because they would have required a completely separate analysis, as they were more procedural in nature, while this analysis has focused on the symbolic interactionist aspects of the consultation – the way that people feel about themselves and are made to feel in that situation, and how these interpretations affect their experience of the encounter. Some of them, such as having an ageing parent, although relevant, were not raised by the service user as an issue. Others, such as self-efficacy and trajectory of illness, were distributed amongst different parts of the analysis, and the codes themselves were not included in the final analysis because they were based more on my prior theoretical perspective than on the data itself. (See Appendix 9 *Original data coding and their destinations* for a detailed explanation of why that theme was discarded or which category it was contained in.)

Following the initial and focused coding, Corbin and Strauss (2008) would then proceed to axial coding, structuring the developing analysis by organising categories into schemes, such as the conditions that structure the experience of health consultations; the routine responses of participants to consultation-related issues, events or problems; and the consequences of actions or interactions in the consultation. However, Charmaz (2006) suggests that this early imposition of theoretical structure can constrain the eventual analysis, so categories were explored in relation to the participants' expression of feelings about (including dissatisfaction with) the consultations. As identified in *What is patient satisfaction and how is it measured?*, it is helpful to identify deficits in care, and to address the aspects of the consultation that evoked emotional responses, as these contain implicit meaning for the participant about the experience. The aspects of the consultation that participants found it difficult to discuss and were even anxious about disclosing mainly related to not liking, or feeling liked or respected by, the health professional; but also included having difficulty in disclosing information to the health professional or achieving understanding in the encounter, due to feelings of guilt, embarrassment, anxiety, or needing more time or further explanation. Some participants were positive about their health consultations, but even where they were happy with their current care, they would often relate experiences that continued to make health consultations potentially stressful

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situations. Consequently, the intention of the analysis is not to suggest that all consultations are overwhelmingly unsatisfactory, but to illuminate some of the fears, anxieties and previous negative experiences of people with learning disabilities, in order to promote understanding by health professionals of some of the vulnerabilities of people with learning disabilities.

Occasionally, throughout the data analysis, examples given from the data to support findings may have the service user identifier and data source omitted in order to protect confidentiality. This is due to the possibility of recognition by service users, service providers and others involved in the data collection process. In addition, quotations are not always used to support points made from the data due to the nature of the conversations, where the meaning was only clear within the context of a long interview or focus group, or from data gleaned outside of the interview itself. Sometimes, verbal communication with someone with learning disabilities does not facilitate the use of a succinct quotation to support a theme, since their expressive verbal ability may be limited, and answers were more likely to be either “yes” or “no”. Additionally, they often assumed that I understood background that was not apparent. This conflicts with the aim of the research being transparent and open, but the data collection and data analysis have been closely supervised and an audit trail is available. Due to the highly identifiable nature of the transcripts, samples have not been included in this thesis, apart from notes from the member check, in order to maintain anonymity. However, full transcripts and data analysis materials are available for external examiners. For the same reason, background information about service users is only given where necessary for understanding of the analysis. The findings were based on the data given and the context of the discussion, in order to ensure that the analysis represented what each category meant to the individual. This has allowed a more in-depth understanding of the service user experience than a thematic content analysis would, and where practicable, the context has been explained in order to support the findings.

The relational analysis (see Figure 4) was reorganised following the member check (see Appendix 10 – *Member check*) and discussion of the findings in relation to relevant literature. Four overarching themes accounted for most of the categories (see Figure 4: Overall relationship between themes in health consultation experience for a person with learning disabilities) and will be discussed in depth in relation to relevant literature: emotional security with the healthcare professional (see chapter three); the role of the other in health consultation experiences (see chapter four); communication barriers –

anxiety, embarrassment and stigma (see chapter five); and past experiences and current perceptions of health encounters (see chapter six), which related all the other themes together and provided a model of the relationship between them. Insights into the process of communication within the consultation were also gained from reflecting on the interview experience (see *The interview experience – personal development, barriers and insights*).

### **Chapter 3: Trusting Relationships and Emotional Security with the Health Professional in the Consultation Experience**



**Figure 1: Trusting relationships and emotional security with the health professional**

#### **Introduction**

Different aspects of the relationship between the service user, the people who accompanied them to or supported them with their consultations, and the healthcare professional with whom they had the consultation, were consistently identified as being central to the health consultation experience. These categories were grouped together to form one of the major themes from the analysis: Trusting relationships and emotional security with the health professional (see Figure 1 above) and will be analysed in relation to the literature in this chapter. A number of the categories that were identified in the data related to how psychologically comfortable or secure the participants felt with the healthcare professional, although they were often combined with practical approaches within the consultation, so could have nuances of meaning. Participants were aware that there was a difference sometimes between behaviours and attitudes, and a good experience in one consultation was not necessarily sufficient to promote service user participation in that encounter. For example, even if a doctor “*talked nicely*” to a participant, they were sometimes still unable to contribute to the consultation due to feeling “*shy*”, although concerns about cognitive limitations and anxiety from previous experiences were found to be inhibiting factors. When participants felt listened to, this could produce a tangible outcome, such as a prescription, or a more subtle feeling of being valued. The ability to express agendas could be seen in terms of the abilities of the service user to understand and respond, or the promotion of autonomy by the health professional,



but it was also dependent on participants' security in the consultation, and the role of another person in the consultation. (See Table 6 for a brief outline of the major categories within this theme, which will be explored in more depth in this chapter) .

<b>Table 6: Trusting relationships and emotional security with the health professional – major categories</b>	
Listening	Includes acknowledgement of service user voice, being offered choice, active response to concerns.  Not listening includes not talking to the person, not responding to their contributions. Participants could not always articulate why they did not feel listened to, but they felt upset and devalued by it.
Cues and prompts in consultations	Includes the importance of actively seeking service user contributions to the consultation and of responding to even slight cues by the service user that they want some involvement. This demonstrates listening and shows valuing behaviour.
Friendly healthcare professional/talks to you nicely	Warmth and friendliness are important, but need to be genuine, and not used to avoid difficult issues – service users are aware of health professionals' feelings towards them.
Involvement in communication/ Inclusion	Difficulty in understanding and communicating can be barriers to involvement, but a lack of trust in the health professional may cause the service user to withdraw from the interaction, particularly if they feel excluded. Exclusion may be due to communicating exclusively with the carer/relative, particularly in order to acquire information.
Expressing agendas	Participants gave examples where they expressed concerns in physiological terms and were given physiological care (ECG to rule out physical cause of pounding heart), but they did not express underlying causes of anxiety, such as fear of consultations or anxiety due to worsening health. Being able to express needs and have them validated, even if the outcome is different to the original agenda, is necessary to feel respected in the consultation. Using biomedical language excludes the service user from the consultation and prevents them from expressing their needs in their own language. It is necessary to trust the health professional before agendas can be fully expressed.
Individual personality/	Liking, feeling recognised by and understood by a doctor are essential to a trusting relationship. Although length of relationship is not

Relationship with professional	sufficient for this, it is necessary. Previous unhappy relationships with health professionals can cause difficulty in establishing new trusting relationships.
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## Listening

Some participants did not feel that they were listened to in their health consultations, but the feeling of being listened to is quite a complex one – some participants described it in terms of whether their contributions were acknowledged in the consultation; others saw it more in terms of the healthcare professional offering them choice or acting in response to their expressed concerns; while some gave examples of cues that were not picked up by the healthcare professional. For example, Rolf explained that, in an annual health check, the nurse did not talk to him and, although he answered her questions, she did not listen to his answers:

H: *And what... Why do you think she didn't look at you?*  
Rolf: *She didn't talk to me,... See if I'm okay.*  
H: *She didn't talk to you?*  
Rolf: *No.*  
H: *Why not?*  
Rolf: *She was talking to somebody.... Somebody else [....] She wasn't listening to me.*  
H: *She wasn't listening to you?*  
Rolf: *No.*  
H: *So you were trying to answer her?*  
Rolf: *Yes, I did answer her.*

Edmund's nurse listened to his concerns about having blood taken, and offered to give him a separate appointment for blood tests, so that he would not be so worried about going for his health checks, but he decided to "*get it out of the way and done with*". By discussing his concerns and offering an alternative, even though the functional outcome was the same, Edmund felt that he was listened to. Jonathan trusts his practice nurse, who makes him feel happy because she listens, but had previously experienced a consultation with a doctor who had not listened to him and "*did not want to know*":

H: *....So it was just this particular doctor who you found rude?*  
Jonathan: *Yeah.*  
H: *Did he talk to you?*  
Jonathan: *Not really.*  
H: *Who did he talk to?*  
Jonathan: *He used to talk to my mum a lot but I...I told him he were quite rude.*  
H: *Mm.*

*Jonathan: And I told him where to go and he didn't like it.[.....]*

*HF: How did that make you feel?*

*Jonathan: Sad.*

*[....]*

*H: Did he respect you?*

*Jonathan: No.*

*H: Did he respect your mother? Was he respectful to her?*

*Jonathan: No, my mum didn't like him.*

He also felt, when talking to a psychiatrist after his mother died, that he was not listened to. Despite questioning Jonathan as to what the differences were in how someone did or did not listen, he was either reluctant or unable to explain it. Penny explained to her doctor that she is embarrassed to talk about sex and that she does not want a cervical smear. However, she does not feel listened to as she keeps receiving invitations for smear tests and she has had difficulty answering the doctor's questions about her relationship with her boyfriend.

Listening is necessary for satisfaction with a health consultation, and has been described in terms of the behaviour of paraphrasing the person's words or feelings (Hancock, Bonner, Hollingdale, & Madden, 2012). These data show it is central to the feeling of being equal and having a valid contribution to make within the health consultation, and involves not only listening to what the service user is saying, but exploring what they mean by it and what their underlying concerns are, as well as responding to them by adapting care to their preferences – this is related to autonomy and control, another overarching category. The data show the different ways in which service users identify that they are not listened to – either because the health professional does not ask them questions that they can answer, or acknowledge their responses, or because the information communicated is not openly discussed or acted upon. These data confirm the findings of Steihaug, Gulbrandsen, and Werner (2012, p. 321) that “recognising behaviour is described at a practical level as listening, understanding, acceptance, tolerance, and confirmation”. The Steihaug et al. (2012) study made a detailed analysis of five videotaped doctor-patient encounters within a Norwegian general hospital (chosen from twenty in various specialities) where the consultation was judged by the researchers to show recognising behaviour. The analysis involved identifying how verbal communication and non-verbal behaviour contributed to the relationship between the doctor and patient within the interaction, particularly focusing on how the doctor recognised the views of the patient. In a recognising consultation, where the patient expressed subtle cues that all might not be well, or that she was concerned about a symptom, and therefore was not

completely convinced of the doctor's advice, the doctor explored those concerns, asked further questions and reassessed the options. The doctor also explained why those concerns, although legitimate, were not extraordinary or contrary to the agreed treatment plan. Thus, the patient's concerns were recognised and, although they did not change the outcome, the patient was satisfied. While listening to the patient was particularly important, because it enabled the doctor to pick up and respond to verbal and non-verbal cues, other key aspects included recognising and acknowledging the patient's views, responding to concerns and providing expert opinion on the costs and benefits of alternative interventions. It is clear from this study (Steihaug et al., 2012) that listening is not sufficient for a good relationship, and a good relationship is not sufficient for a good medical consultation (one where advice is sound and the patient is satisfied with the encounter), but unless the doctor listens, they will not identify concerns and explore them. Consequently, not only will the doctor-patient relationship be unsatisfactory because the patient will not feel listened to or valued, but in addition, they may not be given appropriate advice. The experiences and importance of being listened to by the health professional are shared between the research carried out in general populations (Hancock et al., 2012; Steihaug et al., 2012) and the findings of the current study of the experiences of people with learning disabilities.

### **Cues and Prompts in Consultations**

Listening, or recognising behaviour, therefore requires health professionals to be aware of cues that service users insert into the conversation, without necessarily clearly stating their agendas. Sometimes, participants would express thoughts that were not heard or responded to by healthcare professionals. For example, in an audio-recorded consultation, James responded to being told that he had protein in his urine, as expected, with *"why is there protein in urine? Yeah, you eat, when you eat a lot of stuff, you get protein....that's not bad really? protein in it? nuisance....."* – looking for an explanation of what protein in his urine means and how serious it is for his health. The healthcare professional did not respond to this cue at all, although Salmon, Mendick, and Young (2011) suggest that emotional cues (in this case, the very subtle ones of *"not bad really?"* and *"nuisance"*) indicate clinical concerns. Another cue related to a mother expressing concern that her son's cognitive function, particularly his attention, appeared to be declining. The nurse acknowledged this concern with *"Right"* but did not respond to it in any way – no further questions were asked, no suggestion of referral or assessment was made, and it was not

referred to again in the audio-recorded consultation. There are a number of explanations for this, but by not responding to this cue, the health professional is not actively listening to the mother's concerns, thus limiting her role in the consultation.

At other times, healthcare professionals would prompt service users to express their agendas, often by asking a very general question, for example:

*Edmund: She might ask me questions like er...my exercise and how am I exercising?  
Er...am I keeping up with taking my medication, things like that. Just general things like that: how am I keeping in myself; asking me questions on what I'm eating, am I cutting out on all the greasy, fatty foods, sugar, things like that.  
Just asking me how I'm manag...how I'm managing it basically*

Starting with more general questions allows the service users the opportunity to express their own agendas at the beginning of the consultation. However, if questions are too open-ended, the service user may be unsure of what the healthcare professional is trying to achieve, which is why it is important for the service user to prepare their health action plan or agendas in advance (see *Health needs and inequalities and the development of service provision for people with learning disabilities*).

Traditionally, within a help-seeking consultation, doctors were thought to use a hypothetic-deductive model for making a diagnosis (problem-solving), which involves building a representation of the problem, then using logical decision-making processes (algorithms) to arrive at the most likely diagnosis and optimum management. In reality, there are too many possibilities for human beings to do this (Harries & Ayton, 2007). GPs are faced with presenting symptoms that can be caused by a multitude of problems, so they start by breaking them down into key points, using prior experience to apply a "rule of thumb" or heuristic to decide what the problem is, the likelihood of it occurring and whether it leads to a plausible diagnosis and management plan (Newell & Simon, 1972). Unfortunately, the heuristics that doctors use are not always accurate. For example, colds are common and many cold-like symptoms will be ascribed to having a cold. However, the symptoms can be due to other causes that the doctor does not explore as a result of the heuristic of representativeness. Additionally, if a doctor has a readily available instance of an event (diagnosis) because it was more recent or emotionally relevant, that availability heuristic will bias the doctor towards that diagnosis (Harries & Ayton, 2007). Consequently, the ever-narrowing focus of a traditional medical consultation can be a barrier to effective diagnosis, causing the doctor to ask questions to confirm an early hypothesis, rather than listening to a full narrative and exploring a wider set of possibilities.

The importance of listening carefully, demonstrating by eye contact that the health professional is focused on them, and allowing them to finish talking before responding, was demonstrated in a large-scale European focus group study of what patients want from their doctors during consultations (Bensing et al., 2011), supporting these findings that people with learning disabilities, like other patients in Europe, want to be listened to. The danger of arriving at incorrect conclusions due to not listening to the service user's perspective suggests important medical, as well as psychological, imperatives for careful listening behaviour in health professionals. Given the communication barriers faced by people with learning disabilities (see *Communication barriers: anxiety, embarrassment and stigma*), encouraging and validating service users' agendas is essential to a satisfactory consultation.

### **Friendly Healthcare Professional/Talks To You Nicely**

Whether the health professional was perceived as being friendly affected the quality of the health experience for some participants, and a few described quite negative views of health professionals. There was a range of experiences and expectations of the approach of the health professional from informal unfriendly or informal friendly, professional and friendly, to formal or stern. One participant recalled an incident in the past, with a GP now retired, that was not good, where the GP "swore" (although, of course, what constitutes swearing may be differently understood). More friendly informal approaches include Jonathan's preference for health professionals who are "*happy*" and liking his practice nurse because she "*smiles a lot*". Similarly, Elaine thinks a good nurse is someone who "*looks after you, talks to you nicely and...only does what you tell her to do*", and liked the way her female GP talked to her. Henry, on the other hand, spontaneously identified "*she's alright with me when we were talking about things*" as a positive aspect of his health checks with the nurse, although he refers to her by her professional title of "*Sister*". Ann observed that the health professional addressed her as "*Miss....*" and was quite serious when she went to her practice with a health problem, suggesting quite a formal interaction between people who did not know each other very well. At the most formal end of the spectrum, Matt found that his psychiatrist was "*rather stern*" so he had to be careful what he said to her, while he found his GP, whom he knew, friendly. In this instance, his perception that the psychiatrist was not friendly affected his openness with her, which could reduce the effectiveness of the consultation. However, the relationship between a friendly doctor and a trusting relationship is not straightforward, as participants may perceive a doctor as friendly, without feeling secure enough to take part in the consultation. Even though the doctor

makes Penny feel “*very nice*” because she is friendly and talks nicely, Penny still does not like to talk much because she feels “*shy*”. Some service users talked in terms of liking or not liking doctors – so Rachel just does not like doctors in general, while Henry and Lindsey both like some but not others.

Liking is an emotion that has been shown to be reciprocal in doctor-patient relationships (Hall, Horgan, Stein, & Roter, 2002). Patient liking their doctor was predictive of satisfaction with consultations a year following data collection, in this questionnaire study of people with type II diabetes who all knew their doctor moderately well (Hall et al., 2002). This suggests that physician and patient liking each other is more consistent than satisfaction with a single consultation. Physicians liked patients who were in better health more than they liked those in worse health. Since people with learning disabilities are highly likely to have complex healthcare needs (Lindsey, 2002), this may be one mechanism by which they experience less effective healthcare (Michael & Richardson, 2008). There was also a relationship between being liked by the doctor and liking the doctor, as well as with satisfaction with the consultation, and patient’s perception of better communicating behaviours (Hall et al., 2002). Consequently, where service users do not like or feel secure with health professionals, they are likely to be accurately reflecting the feelings of the health professionals towards them. A narrative analysis of the consultation experiences of 44 people with diabetes (Hornsten, Lundman, Selstam, & Sandstrom, 2005) found that service users were dissatisfied when health professionals did not treat them as equals and mutually agree goals, and were not friendly. They also felt dissatisfied when health professionals did not value them or make them feel safe and confident. The importance of being treated like a person rather than a set of symptoms or a disease was highlighted. In a small study in Australia, three service users suggested that a warm, trusting relationship was essential for good communication in a consultation (Ziviani, Lennox, Allison, Lyons, & Del Mar, 2004).

So, while listening and talking nicely are important, some people may still be too shy to interact in the consultation, and how much doctor and patient like each other is important. This question of which aspects of the consultation were considered more important by potential patients was studied using questionnaires (nearly 1200 datasets in total) that gave participants choices between different aspects of the consultation, in three hypothetical illness scenarios (Cheraghi-Sohi et al., 2008). Overall, they concluded that being given a thorough physical examination was the most valued aspect of the consultation across all scenarios and both questionnaires, with physician knowing the

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patient well coming next in value (Cheraghi-Sohi et al., 2008). The interview data from service users with learning disabilities in the current study show that warmth and friendliness in the consultation can affect their experience and its absence can limit their openness within the consultation, but shyness can prevent full communication, even where the health professional is “*nice*”, if they do not know them well enough to feel liked by them. Another questionnaire study (Moore, 2008), administered within a Nepalese outpatient setting, and asking patients what they wanted from their consultations, found that the friendly manner of the doctor was the most highly valued aspect of the consultation. While Nepalese patients were happy for doctors to be in charge of the consultation, they saw being treated in a friendly manner as very important. They strongly agreed with the idea of being treated as partners in the consultation, and did not value incomplete information-giving or rapid consultations (Moore, 2008).

So, warmth and friendliness are important, but their relative value may differ depending upon cultural expectations, a perception of being liked by the doctor, and other aspects of the consultation. For example, in a grounded theory study of over 100 video-recorded hospital consultations (Agledahl, Gulbrandsen, Førde, & Wifstad, 2011), a friendly, jovial manner could be used to avoid deeper existential questions such as fear of extreme pain, or death and dying. Clear cues about these fears were glossed over and ignored within consultations, allowing the doctor to focus on medical diagnoses and interventions. It is argued that a polite and friendly manner being used as a barrier to deeper emotional engagement may be standard practice within Western medicine, objectifying patients and potentially endangering them both medically and emotionally (Agledahl et al., 2011). This may explain why, in the current study, even though one patient described a doctor as friendly and said she spoke nicely, she was still too shy to take part in the consultation. It could also explain why friendliness does not always rate highly in relation to other patient-centred approaches (Cheraghi-Sohi et al., 2008) and why it is not identified as a major or definitive category within the data from the current study.

In another sense, what might be regarded as friendly with peers could be seen as disempowering in a health consultation. Being called by one’s first name by a health professional reinforces the inequality of the relationship unless they, too, share their first name with the service user, without even the prefix of “doctor” or “sister” (McGregor, 2006). Indeed, as McGregor argued, the process of empowerment itself implies inequality, so:

“It is only when power is shared, via good communication and mutual goals[,] that trust will be established and choices truly explored within an agreed and analogous partnership that must be equally respected and valued by both medical professionals and patients.”

(McGregor, 2006, p. 9)

This question of empowerment, involvement and trust arose as a complex aspect of experiences within the data in the current study and will be explored below (*Involvement in communication/inclusion*).

### **Involvement in Communication/Inclusion**

One of the categories identified by several of the participants was the nature and extent of their involvement or inclusion in the consultation. There was a broad range of verbal and para-verbal communication strategies used by the participants in this study, including the use of a picture board by one person. This resulted in different levels of explanation of their experiences, as well as different experiences to explain. Sometimes the information shared was quite procedural and descriptive. For instance, Roddy described some of the questions the doctor asks (such as if he is sleeping well) and, in just a few words, the answers that he gives. A care worker attends his health checks with him, suggesting that, although the health professional asks him questions, any detailed information was given by the care worker. However, because Roddy has focused on his own interaction, this is only an inference. Nonetheless, Roddy thinks the doctors and nurses at his practice are very good, and is happy that he no longer has fits. This suggests that he is happy with his level of involvement. Kevin has a similar attitude, saying that he has a good doctor, but lets his father “*sort everything out*”. Others describe the pragmatic approaches taken to information sharing in the consultation, giving some evaluation of their role and relative contribution to the encounter. So, Rachel explains that she goes to see a doctor with her carer if she is unwell, relying on the carer to explain her problems, but answering questions if the doctor asks her directly.

For these participants, they were able to answer some simple, factual questions, while their carer was able to provide any information that they were not able to. This could be seen as a relatively low level of involvement in the consultation. Not one service user

mentioned health action planning, a process that is supposed to ensure service user involvement in their own health. This does not mean that they did not contribute to health action plans, or that they were not incorporated into their health consultations, but it does suggest that they have little awareness of their own role in their healthcare, which means they may not see themselves as having much autonomy within the health consultation process. Higher levels of patient autonomy are regarded as a requirement of patient-centred care (see *The effects of person-centred communication on health outcomes*), including encouragement to express agendas, promoting informed choice and being non-judgemental. Lee and Lin (2010), in a longitudinal questionnaire study of people with diabetes ( $n=396$ ), found that perceived autonomy support was related to patient trust in and satisfaction with their physician and better perceived psychological well-being. This effect was much stronger where patients wanted to take more control in decision-making, but those patients also had less trust overall in their doctor (Lee & Lin, 2010). This could be problematic for service users with learning disabilities who may find it more difficult to understand and take part in decision-making. Health professionals and carers need to work harder to explain choices and their implications, for people with learning disabilities, who historically are more likely to have had poorer healthcare (Michael & Richardson, 2008).

Catherine, who lives in partially supported accommodation, unusually, went for her health check a couple of times independently. She now goes with a support worker, but does most of the talking herself. She likes it that the doctors and nurses mostly talk to her, but prefers that her support workers attend with her and help to remember what has been said. However, when Catherine goes to hospital, a member of the support staff always goes with her to tell the doctor what they have observed about her health problems, and Catherine feels that she would not be able to do without them there. So, in a situation where she feels more secure, in her GP practice, Catherine feels more in control, but in hospital, where she does not know the health professionals, and they do not know her, she needs the support staff. So, knowing and being known by health professionals promotes involvement in healthcare for Catherine.

It might be expected that, due to limitations in understanding and verbal communication, the level at which participants could be included in the consultations is lower than with the rest of the population, and that participants were satisfied with this. For example, Lindsey explains that she does not always understand what the doctor or nurse says to her, so she takes her mother or her carer with her so that the healthcare

professional can explain it to them. However, later in the same interview, she described one consultation with a doctor that reveals the complexity of inclusion:

*Lindsey: So we went in to see him, he's a male doctor, I think his name was Dr (surname), we went to see him, the doctor wants to speak to me, but not me mum. So he speaks to me, me mum likely said something to him, and he said "stop there.". He said "stop there." Oh, and he's "talking to me, and not me mum". He's... Some of them are very rude. Some doctors are fine, some doctors are not.*

In this situation, when the doctor tried to focus exclusively on Lindsey in the conversation, Lindsey felt offended, not empowered. Although some people with learning disabilities want to take part in consultations and be included by the health professional (Gates, 2011b), they do not all feel able to do so. Where someone with learning disabilities trusts their carer, and feels able to communicate with them, this allows the carer to represent them in the consultation, particularly if they are lacking in self-confidence in that situation. Where the health professional blocks this indirect communication, it can reduce the service user's trust in the health professional and make them feel powerless because they do not have an advocate who can negotiate for them. Thus, although the doctor may have been trying to empower Lindsey for herself, he had the opposite effect.

The data from the current study clearly show that communication with health professionals can be problematic, a view supported by focus groups of people with learning disabilities ( $n=23$ ) in a review of what they wanted from care (Gates, 2011b), which found that, not only was there limited use of "easy-read" materials, and a lack of specialist knowledge by health professionals in acute services, but also that they sometimes ignored the service user and spoke only to their carer. In an Australian study of communication in health consultations ( $n= 17$ : three service users, five GPs, seven support workers and two informal carers), service users were disappointed at the lack of eye contact and apparent reluctance of GPs to examine them, and wanted to be treated in an age-appropriate manner, rather than being excluded from the consultation, or treated like a child (Ziviani et al., 2004). To compare involvement and empowerment for participants in the current study with those of the general population, it is useful to look at an interview and focus group study of a general population that identified people's preferences for involvement and participation in health consultations (Thompson, 2007). This identified a hierarchy of "patient power" or involvement and participation in consultations. Thompson's (2007) study showed that people choose a varying level of involvement, depending on the severity and acuteness of need (higher involvement with less acute, less severe illness), their trust in

the healthcare professional (generally a lower need for involvement with greater trust) and their personality or self-confidence within the situation (more confident, active people wanted more involvement). Trust in the healthcare professional includes how well they know them, and how positive their previous experiences of healthcare have been.

In Thompson's (2007) study, few people aspired to the highest power level of *autonomous decision-making*, though some respondents wished to exercise informed choice within a *shared decision-making* process in partnership with health professionals as they thought it would result in better health outcomes. Some people simply wanted to be involved in an *information-giving/ dialogue* consultation, where their experiences and preferences were taken into account within the consultation, while at the lower involvement level, some people thought that only being involved at an *information-seeking/information receptive* level was a standard expectation, which was not always seen as satisfactory. In the current study, service users often chose (or needed) to be accompanied by formal or informal carers when they attended health consultations, and the level of involvement that they chose or were able to achieve varied from virtually no involvement, where their carer spoke for them, to seeking support with specific health concerns (post-bereavement depression, dysuria) and actively working with the health professional to change health behaviours (exercise, diet). Some service users wanted more involvement in the consultation, as their concerns were not being addressed, but others were happy that their carer should represent them. Some health professionals actively involve service users in their consultation, but others do not, and if people do not feel respected or valued, this will reduce their ability and motivation to contribute to their health consultation and express their agendas (Barry, Stevenson, Britten, Barber, & Bradley, 2001). Thus, while empowerment may be a goal for a consultation it is not necessarily the most important or attainable goal for the service user, who may be more concerned about how the health professional makes them and their carer feel. This is supported by an interview study that showed that people were more at ease with having greater involvement in the decision-making process if they trusted the doctor and had a good relationship with them (Smith, Dixon, Trevena, Nutbeam, & McCaffery, 2009).

This interview study (Smith et al., 2009), which asked 73 adults living in Sydney, Australia, how much involvement they wanted with decision-making in their healthcare, divided the respondents up into higher or lower levels of education and health literacy. They found some differences between the two groups, with people in the lower education sample seeing their involvement as one of taking responsibility for consent to, or refusal to

follow, the doctor's recommended option. Unlike those in the higher education sample, they did not seek confirmation of the advice or information about alternatives, so they had less choice and, although they may have challenged the practitioner, they generally either accepted the opinion or sought an alternative practitioner for a second opinion. They were more likely than the higher education group to seek support for their decisions from friends and family, and less likely to see themselves as a source of support to others. The key requirement of their involvement for both groups was that they wanted respect for who they were within the consultation (Smith et al., 2009). This supports the findings from the current study which suggests that participants need to feel secure with the health professional before they are able to become involved in the consultation.

When Rolf and his mother went to see the male nurse, the male nurse asked all the questions of Rolf's mother, who became upset about this, and told the nurse "*you can talk to me, but you should talk to him as well*", after which the male nurse did talk to Rolf. Similarly, Elaine did not want her current doctor at first, partly because he talked to her mother, and not to her. However, her mother intervened and suggested that the doctor ask Elaine her name, and once he realised that she could talk, he included her more in the conversation. In the past, Jonathan attended a consultation with his mother and was not included in the conversation, to the point where he and his mother were so upset that he "*told the doctor where to go*" and his mother made a complaint about the doctor. These experiences illustrate what can happen when the overriding aim of the consultation is to gather information on which to base a health intervention plan. In these examples given by Rolf and Elaine, the healthcare practitioner did not talk to them and acted as if they were unable to answer questions or even contribute to the consultation. Although the carer intervened to promote their autonomy in each case, both they and their carers were upset. This is supported by a large focus group study in the United States of America ( $n=18$  service users with learning disabilities, 41 carers and 57 community support professionals), where if service users were not given the opportunity to take part, it caused dissatisfaction (Ward & Stewart, 2008). In Murphy's (2006) study, service users identified that they preferred to be the main person in the consultation, with their carer to support them. This is mostly, but not always, borne out by the data in the current study, with two female service users expressing that they were "*shy*" with doctors and preferring their carers to have more involvement in the consultation.

This shyness could be explained by Thompson's (2007) study, where some people adopted a role of *non-involvement* because of lack of confidence in their own knowledge

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and felt it was best to trust the doctor, or because of the effort and responsibility required to be involved, or because of feelings of alienation with the health service and other institutions. This choice not to be involved could be “due to vulnerability, lack of interest, or apathy, although even for these patients it may represent a deliberate act of detachment, of even defiance, in the face of perceived social or personal exclusion” (Thompson, 2007, p. 1306). Of the two service users in the current study who did not want to take an active role within their consultation (specifically with the doctor), both had identified previous negative experiences of healthcare that affected their ability to trust the doctor. Penny had been given a smear test, without warning or explanation, which caused pain and bleeding, and she now gets “scared” and “sick” when she goes to see the doctor. Lindsey had experienced a needle being stuck in her, as well as having to get undressed for an examination by a male doctor who, when she told him that she was embarrassed (“*He’s not even very happy if I do say to him*”), did not seem sensitive to her feelings. She also expressed the fear that she did not understand a lot of what the doctors said. So, when she goes to see the doctor, she prefers her carers to speak on her behalf:

*Lindsey: They ask the other people what I think of it.*

*H: Right, and that’s better for you is it?*

*Lindsey: It is really, and they explain to me after...*

Thus, while not wanting to be involved in communication could suggest a trusting relationship by someone who is satisfied with their healthcare, in the current study it is more likely to suggest a feeling of helplessness and inadequacy, demonstrating avoidance or possibly defiance of the professional role.

. Edmund felt that he has more self-directed involvement in all the decisions made about his health. **He is given opportunities to introduce any concerns he has rather than having to respond to a checklist.** Sometimes, his health facilitator attends with him, but Edmund still answers most of the questions himself. Penny now feels involved in her health consultations, with both doctor and nurse. The doctor says hello to Penny and talks to her first, asks her how her weight is, how her blood pressure is and asks “*are you doing well?*” When Penny goes to see the practice nurse for her health check, the practice nurse asks if she is alright, giving her the opportunity to contribute. Similarly, with Jonathan, the practice nurse writes down the key points of the health check consultation for him so that he has a record that he can refer to and discuss with other people if he wants to. Although the practice nurse asks the carer questions, she asks Jonathan the same questions, giving him the opportunity to contribute. These data support the view that, while participants in this

study want to be treated as a person and included in the consultation, the level and type of inclusion may vary depending on their own wishes, those of their companion in the consultation and the approach taken by the health professional.

Whereas participants may be limited in their ability to communicate and understand healthcare needs and choices, it is clear from these examples that some healthcare professionals do attempt to include them in the consultation. Where service users are reluctant to take part, this may be due to lack of security in the relationship, which cannot be overcome by simply asking the carer not to answer for them. Indeed, insistence on this can further undermine self-confidence and trust within the consultation, both necessary conditions for the creation of autonomy (Smith et al., 2009). Some practitioners, before they knew the participant, focused on information-gathering at the expense of inclusivity, talking only to the carer. This assumption, by some healthcare practitioners, that carers will speak for the service user is supported by a focus group study of communication with people with communication disabilities in primary care (Murphy, 2006). Homogeneous focus groups of people with learning disabilities, people with aphasia and primary care staff, including GPs, were asked about their perceptions of communication within the primary care consultation (Murphy, 2006). This study uncovered the underlying views of the healthcare professionals, ranging from trying to include the service user in the conversation so that they don't feel "like an ornament" while everyone else talks around them, to thinking that there are not a lot of people giving them communication problems because the carer speaks for them (Murphy, 2006, p. 52). This understanding of communication as simply being able to give information is very low on Thompson's (2007) hierarchy of autonomy within consultations, and suggests that some health professionals may place a low value on the importance of relationships in the consultation.

### **Expressing Agendas**

Throughout the data analysis I have first discussed the findings from the data, generally using the language used by participants, then discussed how the findings relate to relevant literature. This follows the order of discovery, so that it can be seen that the findings and conclusions are grounded in the data. However, the category of *Expressing agendas* is not in the language of the participants and was not solely derived from the data. The current study was originally devised using a discourse analysis approach based on a study of unexpressed agendas by patients from the general population consulting their GP (Barry et

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al., 2000). Consequently, this code arose because of the initial interview schedule, and although it derives from a different conceptual approach, it still relates to the other experiences within the analysis. To remove it would have been *post-hoc* dissimulation. Consequently, the category will be discussed, but its use in the study will be discussed in relation to its theoretical basis, discourse theory, before the data within the category are analysed.

Barry et al. (2000) explored patient agendas in pre-consultation interviews, audio-recorded the consultation and used follow-up interviews to explore the effects of the discourse, focusing largely on the health behaviour outcomes. The focus of the current study changed early in the data collection process for two reasons. Firstly, because of difficulty in gaining access to health consultations via GP practices, but also because it became clear from the first interview that there were more factors influencing the service user's experience of the consultation than that consultation alone. Indeed, the symbolic interactionist basis for the analysis required investigation of antecedent factors on the interpretation of the encounter. Thus, the method of identifying unexpressed agendas and relating them to health outcomes was inconsistent with the goal of the research, to understand the experience from the service user perspective. Apart from one observed consultation between a participant, parent and advanced nurse practitioner, the data from the current study are based on focus groups and interviews where participants gave their perspectives on the experience of health consultations. This necessarily means that the perspective of the health professionals is not included, but comparisons can be made with the literature on consultation discourse, provided the differences in perspective are acknowledged. Participants were asked about expressed and unexpressed agendas, and their responses are discussed following an outline of medical discourse assumptions.

Expressing agendas is fundamental to the medical discourse approach, necessitating some review of its theoretical background to facilitate clear discussion of the data analysis. Consultation discourse analysis focuses specifically on the biomedical perspective and "lifeworld" perspective, evidenced through the language used by doctor and patient (Mishler, 1984). The physician's perspective is powerful because, as well as influencing clinical decision-making and access to care, it is the one that is recorded in the notes, thus influencing future consultations:

“There are no external checks on possible distortions or misunderstandings, or of different perceptions by patients of what has been said, or left unsaid.”

(Mishler, 1984, p. 10)

Thus, Mishler argued, research which had, to that point, focused on the structures, recorded processes and outcomes of medicine, needed to examine the communicative actions of participants in medical consultations. This methodology is based on the critical sociology theory that the purpose of communication is to achieve a mutual understanding, but the dominance of instrumental rationality (scientific knowledge used to identify the most efficient means to achieve a goal), a perspective into which the doctor has been socialised and which is reinforced by their professional role, has disempowered the individual within the discourse (Habermas, 1987). Their “lifeworld” communication, and therefore their individual goals within the interaction, are subordinated to the goal of efficient health outcomes, resulting in mutual understanding not being achieved (Mishler, 1984).

Communication in consultations is a “core component of clinical work” and, he argues, can only be fully understood by directly observing and recording consultations (Mishler, 1984, p. 12). Thus, the doctor and patient are seen to have different aims or agendas for their communication within the health consultation. Levenstein et al., (1986, p. 25) define the patient’s agendas in a consultation as their “expectations, feelings and fears”. They explain that, in patient-centred medicine, the doctor must reconcile the patient’s agendas with their own agenda of diagnosis and health intervention, but that, as patients do not always make their agendas explicit, it is the role of the doctor to understand the patient’s perspective. This is achieved through facilitative approaches and responding to cues, to encourage the patient to express their agendas. From this epistemological standpoint, the current research has a paucity of observed consultation data, with only one consultation being observed, so discourse analysis is not possible. However, the focus is on the service user experience, so evaluation of the discourse does not lie in the rational view of an observer of a snapshot in their life, but in the service user’s idiographic perspective involving their reflexive experiences of health encounters, as understood by the researcher (with the necessary limits on objectivity).

The categories of expressed and unexpressed agendas were identified, but explored not just for their effects on health outcomes, but for why they were or were not

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expressed, and what effect that had on the individual in their view. Thus, where participants in the current study stated that specific agendas had been expressed, the data have been given, but service users were not always able to remember and recount specific instances within their consultations. For example Catherine stated that she can talk to her practice nurse and tell her anything, but did not give examples, while Roddy could not recount his questions about seizures:

*H: What... What were your questions?*

*Roddy: About... About having fits and absences... I don't have any fits now.*

*H: No....*

*Roddy: I have nnn... Absences.*

The language participants used to explain the issues they discussed with the health professional sometimes echoed the language of the consultation. For example, Ann told the doctor that she *"could not stop going to the bathroom"*, the physical health agenda that she had been able to express. However, when interviewed, she said she wanted to see the doctor more frequently and that she wanted to know why her seizures were getting worse, but had not asked the health professional at her last health check. This suggests that she is unable, within the consultation, to ask questions about her health concerns, but her role is more about describing symptoms, indicating a low level of involvement (Thompson, 2007). Penny told her practice nurse that she was aware of her heartbeat being unusually strong, so she was given an electrocardiogram (ECG), which turned out to be normal. Again, the expressed agenda is responded to as a biomedical concern, which does show the person that their concerns are taken seriously and investigated, but it could also be interpreted as a psychological concern.

An interview study of 20 patients attending a cardiac outpatient department for palpitations (Gordon, Vincent, & Bowskill, 2008) found that only 11 felt they had a satisfactory explanation for their palpitations. No patient mentioned an explanation of the role of anxiety, despite its role in the disorder, with explanations focused on explaining the physical cause, if found. However, eight patients did not have an identified physical cause. Penny said in her interview that having her blood taken, which happened at every consultation, made her feel physically sick, but she had not told the health professional. So, even when agendas are expressed, the service user may feel that their feelings are not relevant because they are only responded to in a biomedical way, when concerns may also need to be acknowledged and understood emotionally, and the possible relationship between the two explained. Conversely, a checklist assessment of health needs for 59

adults with learning disabilities and their matched carers (Turk, Khattran, Kerry, Corney, & Painter, 2012) found that they reported significantly more pain and were less likely to discuss this with someone than their carers. They also had other physical health problems that had not previously been identified, emphasising the importance of a full physical assessment including specific questions about pain.

As we have seen in *Cues and prompts in consultations*, it is important to make physiological assessments and not assume that a problem is psychological, but since psychological factors can cause or exacerbate or increase awareness of physiological symptoms such as pain (Turk, Swanson & Tunks, 2008), it is also necessary to address the person's psychological needs. Chronic stressors are likely to increase a person's susceptibility to the effects of stress on health (Ayers & Steptoe, 2007), so it is possible that the stigma perceived by a person with learning disabilities (Paterson, McKenzie, & Lindsay, 2012) could make them more susceptible to ill health. By acknowledging the person's feelings and treating them as valued within the consultation, the health professional is improving psychological and physical health outcomes, as well as acting in an ethically acceptable manner to promote equity of access to all aspects of care.

Some positive experiences were given, such as when Jonathan had been to his practice nurse to discuss an operation that he had been offered, and she had explained it to him so that he was able to make the decision that he did not want the operation. He had also asked her for an influenza immunisation and been given it. In addition, he had been to see her to discuss personal issues related to bereavement and family problems. He contrasted this with previous negative experiences within institutional psychiatric care. This suggests a high degree of emotional security with the practice nurse. He feels that the practice nurse knows exactly what she is doing, that he can trust her to do a good job, and that he can talk about any health worries with her better than he can with his residential carers. He attributes this to her being female; he finds her better than a doctor because sometimes they can "*say the wrong things*". In addition, she has known him and his family for many years. By being able to give positive examples of telling the practice nurse about his concerns and having them responded to in a way that met his needs, Jonathan not only achieved better health outcomes, but his view of himself as a credible patient was reinforced (see *Embarrassment* section).

Henry was disappointed at not being prescribed antibiotics when he went to see the doctor with a cough or other upper respiratory symptoms. He was not given any

medication at all and was not satisfied with the outcome. He does not understand why antibiotics were not recommended for him.

Henry: *...Then I might have got something, but... white... She asked me about... "Does it come out green?" she said. I said "No, it doesn't come out green, it just comes out white". She said "Oh, I can't give you anything for it then"*  
H: *Hmmm*  
Henry: *So that was it*

Rachel was disappointed not to be given antibiotics for a cold that was affecting her breathing:

Rachel: *Well, I went yesterday, because I was all bunged up and I had a co-cold, and it's on my chest, and she wouldn't give me anything!*  
A: *Exactly the same here.*  
Henry: *That's what he's done to me, I went the...*  
Rachel: *Yeah, and (doctor's first name). I told her, I told her how I was feeling, and she's give me an inhaler to put up, and the ear drops, because...*  
A: *That wasn't the doctor though, was it?*  
Rachel: *Yeah, it was a lady doctor, Dr (doctor's first name).*  
A: *She won't give... Did she give you something in the end?*  
Rachel: *Yeah, but she wouldn't give me anything for the cough, but she said. If it's no better with me inhaler spray, I've got to go back and see her again, because she said they can't syringe your ears.*

For Rachel and Henry, it is unclear how much explanation they were given, but they both felt that they should have been given antibiotics and did not understand why the doctor had not prescribed them, so their agendas were not responded to. Henry asked the doctor for something for his cold, but did not specify antibiotics; Rachel did not say if she had asked for medication. Rachel's doctor did explain to her that she should go back if the symptoms did not resolve, but Henry did not identify that from his experience. The doctor in each situation achieved their agenda of not prescribing antibiotics for an uncomplicated respiratory infection, but both service users were not in agreement with this, so the communication did not achieve mutual understanding. Consequently, the service user has been effectively disempowered within the consultation because they perceive that the doctor did not engage with their lifeworld perspective (Habermas, 1987) of why they needed antibiotics. The effect, though, has outlasted the illness episode. Even if the prescribing outcome had remained the same, if Rachel and Henry felt that their agendas had been acknowledged and discussed until a mutual outcome had been agreed, they would have felt that their agendas were respected, and by extension their value as human beings (Steihaug et al., 2012). Conversely, not feeling valued as a human being could lead

to withdrawal from the consultation process (Thompson, 2007). If all agendas cannot be met in one consultation, it is good practice to prompt the service user to make another appointment, but neither person had their perspective explored sufficiently to address their concerns about not having antibiotics prescribed (Mauksch, Dugdale, Dodson, & Epstein, 2008).

Matt went to see his GP with a knee problem, and asked for a physiotherapy referral. Instead, he was prescribed an anti-inflammatory cream to apply to the knee. He thinks he was given the cream because it was too expensive for the GP to refer him for physiotherapy, and his family later paid for him to see a physiotherapist privately. He perceived that the GP did not engage with his views, and consequently he and his family withdrew from the health consultation process and paid for their own healthcare. He viewed the doctor as a gatekeeper to resources, and felt that he was inappropriately denied access to them, suggesting a feeling of injustice. As Haugli, Strand, and Finset (2004) found, in their focus group study about medical encounters with people with rheumatoid arthritis or fibromyalgia, key aspects in their relationship with their primary physician involved being seen as a person and being believed, that is, having their experiences validated. The issue of paying for private physiotherapy may be seen as less damaging for Matt and his father, than their perception that the doctor did not validate their view of the health problem (but see *Multiple service providers* for an additional reason).

In a study of voiced agendas (within audio-recorded consultations where the GP identified the symptoms as medically unexplained), Salmon, Dowrick, Ring, and Humphris (2004) found that most patients either asked explicitly for explanations as to what might be wrong with them or gave subtle cues that they would like an explanation, but these were mostly ignored by the GP, or they were sometimes given superficial reassurance. They found that, where emotional or social issues were voiced, the GPs generally blocked those agendas, either by refocusing the conversation on physical problems, or by reframing the issue within a normal context to minimise it, or by pointing out what the patient could do to resolve the issue themselves. While most of the participants in the current study were not consulting about medically unexplained symptoms, they also describe their issues as not being responded to. In the current study, where participants said their agendas were responded to, there were three types of response: the problem was medically examined to rule out an underlying somatic cause; the issue was assessed in depth before prescribing appropriate medication; or detailed explanation was given to allow the participant to make a choice.

In all cases where the person's agendas were responded to and taken seriously in the current study, they were involved in the decision-making process and they expressed satisfaction with the outcome. The health action plan does, to some extent, allow people with learning disabilities to prepare their agendas in advance, and it is advised that the process and the plan should be person-centred and supported by a facilitator who knows the person well (Department of Health, 2008). However, apart from preparation by the health facilitator for a few participants, some do not seem to have participated in setting agendas. In addition, written agendas may not focus the consultation or ensure that the most important issues are prioritised, but may make the consultation longer (Hamilton & Britten, 2006). This may be helpful if extra time is allocated for the consultation, if the health professional responds to and engages seriously with the service user's agendas, and if the health action planning process reflects the service user's agendas accurately. In situations where the service user is accessing acute services, they may not have much time to prepare their agendas, so health professionals would need to be skilful in identifying and responding to them sensitively. Other people may attend with the service user, which makes the question of expressing agendas more complex. This will be considered below and in another section (*The role of the other*).

While having expressed agendas blocked within the consultation reduces involvement in the consultation, analysis of the consultation alone can only explore those agendas that patients actually express. In the current study, participants identified issues that they had not been able to express within their health consultations. One service user said he was too shy to talk in his health checks:

H: *Would you like to have said something?*  
Daniel: *Yeah.*  
H: *What would you like to have said?*  
Daniel: *A lot of things, a lot of things. A lot of things (sigh). [...]*

One participant explains that she cannot talk to her father or carers about "personal stuff", and she cannot tell the doctor without support. She is also unable to express her agendas because she is frightened that the doctor would not like it:

Lindsey: *Well the doctor's... If I speak out at the doctor's, he won't be pleased... If I say anything to them... The doctors won't just want to see me... Ever again... If I say... You know, do say it out with him.*  
H: *...And do you think... What do you think would happen if you did say to a doctor, "this is what I think", or "this is what I want."?*  
Lindsey: *I don't... I don't know now...*

Mark suffers with headaches, and is worried that he may have “*something on the brain*”:

H:           *So, do you tell, errr, about your headaches?*  
Mark:       *No.*  
H:           *Why don't you tell her about your headaches?*  
Mark:       *Ermm, I don't know.*  
H:           *Have you told your mum about the headaches?*  
Mark:       *Ermm... Yeah... Yeah I have yeah.*  
H:           *Does your mum tell the nurse about the headaches?*  
Mark:       *No... No, (pause)*  
H:           *Do you want her to?*  
Mark:       *(pause) Yeah.*  
H:           *Yeah? Would you like to tell the nurse?*  
Mark:       *Yeah.*

So, even though Mark has told his mother about his headaches, she has not told the nurse, and he would like her to. Even though I had only known Mark for a short while, he was able to tell me about his health fears, yet he had never been able to tell a health professional, and his mother had either chosen not to or felt unable to. Similarly, Ann wanted to ask the nurse at her health check why her seizures were getting worse, but neither she nor her paid carer did. These examples suggest that agendas like wanting to understand health prognosis and explore health fears are not expressed in health consultations for people with learning disabilities, either by the person or their carer. For these types of agenda, it is possible that they may be viewed as having health anxiety, which can make patients less liked by their doctors and result in their concerns not being taken seriously (Hatcher & Arroll, 2008). It may be that, in order to present themselves (or for the carer to present them) as likeable or credible, and therefore have better consultations (Hall et al., 2002), participants and their carers did not express all their agendas, even when they were clearly a source of anxiety. This question will be considered in more depth in the section on *Embarrassment*. Understanding, memory and expressive language difficulties can all create extra barriers within the consultation – the companion can help to overcome these barriers, but their role is a complex one and will be discussed in the *Role of the other* section.

These findings are supported by Barry et al. (2000) who carried out pre- and post-consultation interviews, in addition to audio-recording the consultation, allowing comparison between agendas, unexpressed agendas and health outcomes. Out of 35 patients, most had five or more agendas and only four expressed all their agendas in the



consultations. 14 participants had problem outcomes, 12 of them related to not expressing agendas, generally about medication, leading to the conclusion that expressing these agendas could improve drug adherence. The most common unexpressed agendas in the Barry et al. (2000) study were: worries about diagnosis or prognosis; theories about diagnosis; and symptoms. Even though the dominant language was biomedical, patients did not always express even their somatic agendas, with nine patients not describing all their physical symptoms, and nine not requesting the prescriptions that they wanted. In the current study, Rachel and Henry were unhappy with not being prescribed antibiotics; Daniel, Mark and Ann described not expressing their worries about diagnosis or prognosis; and Mark's fears of his headaches being caused by "*something on the brain*" were not shared with his doctor.

In the Barry et al. (2000) study, the consultation language was largely biomedical, which is potentially a greater communication barrier for people with learning disabilities, who often already have limited understanding of language (Mee, 2012). There are several instances, in the current study, of the language used by health professionals being inaccessible to participants, as with James (see *Cues and prompts in consultations*) wondering what it meant that he had protein in his urine, or even where the health professional attempts to use language that the service user might use, but simply imposes a different language ("*boobs*" and "*balls*") which the service user did not like. Grace was unable to follow one doctor, which would have made expressing agendas difficult:

Grace: *I couldn't understand anything what he were saying, so I went to the nurse after that – at least I can understand what she's saying to me.... Sometimes it's too quick isn't it what they're telling you....*

Even when I interviewed Ann, I used the term "*breast self-examination*" and Ann equated that with "*breast screening*" and thought I was talking about a mammogram, so ensuring that health professional and service user understand each other's language is a key aspect of being able to express agendas and achieve mutual understanding, which participants in the current study have identified as important.

James' mother describes him taking to foreign travel "*like a duck to water*" and learning different languages, and he clearly makes attempts to understand and engage with the medical language, but his cues are not picked up. In a later paper, Barry et al. (2001) concluded that even where the patient also spoke exclusively in the voice of medicine, the outcomes were sometimes seriously impaired because agendas relevant to adherence were

not raised. In two consultations with children, the interaction with the parent was in the voice of medicine; the doctor only spoke in the lifeworld voice with the child for “the purpose of gaining co-operation for a physical examination” (Barry et al., 2001, p. 493). Being understood by and understanding the health professional seems to be important to the participants in the current study, but this can only be achieved if the health professional makes an effort to relate the voice of medicine to the lifeworld language of the service user, and to engage with their lifeworld voice in order to achieve this mutual understanding. This takes time (Mee, 2012) (see *Consultation length*), and an understanding of the communication abilities of the service user, which requires the development of a relationship with the person. It also requires commitment and an attitude that values the person, as inclusion cannot be achieved through a health action plan and an annual health check alone.

The health professional being friendly and talking in the lifeworld voice in order to gain co-operation does not value the personhood of the service user if some level of understanding is not attempted. A review of the literature on relationships and communication in the efficiency of medical encounters, that is, where the quality of the consultation was improved within the same or shorter time, or where the consultation length was shortened without reducing quality. (Mauksch et al., 2008) concluded that less efficient consultations occurred where physicians felt pressed for time, where they did not agree agendas early on with the patient, and where they did not solicit the patient’s views on the illness. Better outcomes in terms of patient satisfaction, adherence to advice, or medication, better health outcomes, lower health costs and reduced litigation were achieved when physicians were “person focused, reflective and curious” (Mauksch et al., 2008, p. 1392) and, where they had time, tolerance of silence improved outcomes. This may be because silence prompts the service user to contribute, and Cegala, Street, and Clinch (2007) found that where patients participate more in the consultation and ask more questions, the physician is likely to give more information and verbal support. Their study, based on pre-determined thematic discourse analysis, did not explore the role of relationships. This perspective suggests that patients should be given training to promote their participation in consultations and enable them to express their agendas, a suggestion supported by Edmund’s experience:

H: .....Did [the health facilitator] help with your health check?  
Edmund: Yeah he does, yeah. Before we’ll go anywhere he’ll sit...he’ll sit down with me for a little while, go things...go through things with me to make sure I

*understand, things like that, yeah.*

H: *Yeah. And do you find that helpful?*

Edmund: *Yeah I do, I do I suppose, yes.*

However, not all service users feel able to express their agendas and, as Malpass, Kessler, Sharp, and Shaw (2011) found in their longitudinal interview and consultation study of ten GP-patient pairs consulting over anti-depressants, this may not be because the doctor wants to take the lead in decision-making. Indeed, they identified situations where the person wanted advice on whether they should take anti-depressants, but did not ask for it, and others where they wanted anti-depressants but did not ask for them. They suggest that people with depression are likely to contribute less and feel able to make fewer decisions in consultations, and identify that of the 23 unvoiced agendas over the six-month period, none of them were from patients who knew their GP well at the beginning of the study, 15 occurred with a new GP-patient relationship and 16 of the 23 remained unvoiced by the end of the study. Sometimes, suicidal thoughts were not expressed because patients did not want their medication changing, highlighting the fears patients may have that doctors will make decisions without consulting them, even though the doctors interviewed thought the patients had more overall control. The research seems to show that a rule-based approach to training doctors to behave in ways that elicit agendas and training patients to express their agendas may not be effective, but that the length and quality of the relationship between the health professional and the service user may be the most important factor in achieving mutual understanding in the consultation (Barry et al., 2000; Mishler, 1984). This suggests that how well people know their GP has a significant effect on whether they express their agendas, particularly in a situation where they may feel vulnerable, such as in monitoring anti-depressant therapy. This is supported by the data from the current study, where Matt, for instance, was unhappy with the GP out-of-hours service because he would be transferred to someone who did not know him. This category of the individual personality of the doctor/relationship with the doctor was found in the data, and will be explored in the next section (*Individual personality/relationship with health professional*).

Another way of identifying involvement in the consultation is by coding the content or interaction purpose, in order to identify the types of communication used by both service user and health professional, and relate these to outcome measures, such as patient satisfaction and patient enablement. Pawlikowska, Zhang, Griffiths, van Dalen, and van der Vleuten (2012) used the Roter interaction analysis system (RIAS) (Roter & Larson,

2002) to analyse 88 video-recorded UK GP consultations. This tool is loosely based on the social exchange theory premise that investment in relationships is based on a cost-benefit analysis. It suggests that health professionals' communications can be either task-focused (information-seeking and -giving) or emotion-focused (relationship building and partnership building) (Roter & Larson, 2002), while patients can communicate to gain knowledge and understanding related to their disease or to be understood.

Pawlikowska et al. (2012) carried out a regression analysis of RIAS codes, followed by body language codes, followed by emotional categories, to identify significant factors predicting high or low patient enablement scores. The highest significant variable, the doctor counselling the patient over their medical condition or its management, accounted for 7% of the variance. The overall analysis, including other significant variables of either participant showing agreement or understanding, either participant giving compliments or approval, the patient requesting services, either participant laughing or joking, the doctor making legitimising statements and the doctor having relaxed hands, accounted for 33% of the variance in which patient enablement group (high or low) the patient had rated themselves in. So, the global scoring of the meaning of the interaction did not have statistical significance, and the only body language code of significance was how relaxed doctors' hands were (not using the computer). However 89% of those in highly person-centred consultations on the RIAS scale scored highly on patient enablement, compared with 24% of those who had poorly patient-centred consultations, suggesting that there is a correlational relationship between a person-centred consultation and a feeling of self-efficacy. High verbal dominance by the doctor was also half as likely as verbal dominance to be related to patient enablement (Pawlikowska et al., 2012).

Another study (Peltenburg, Fischer, Bahrs, van Dulmen, & van den Brink-Muinen, 2004) claimed to combine the agenda-setting approach from the medical discourse tradition, analysing the convergence of the voice of medicine and the lifeworld voice in order to achieve mutual understanding, with the social-exchange-theory-based observational approach of measuring communication excerpt styles and purposes within consultations (Pawlikowska et al., 2012; Roter & Larson, 2002). Pre-consultation questionnaires ( $n=2243$ ) identified whether new agendas emerged in the consultation and to what extent the emergent agendas were biomedical or psychosocial (Peltenburg et al., 2004). It was hypothesised that the number of emergent agendas would be affected by different variables, including the history of the patient-doctor relationship and the content

and process of their relationship, assessed from the consultation videos using the RIAS coding system (Roter & Larson, 2002) (see Table 7).

<b>Table 7: Variables measured against number of emergent agendas</b>
(Peltenburg et al, 2004)
(1) Characteristics of the healthcare system
(2) The patient's or physician's sociodemographic variables
(3) The history of the patient-physician relationship
(4) The patient's self-assessment
(5) The physician's perception of the patient's actual problem
(6) The content and process of the physician-patient communication.

In the Peltenburg et al. (2004) study, 68-84% of people had their agendas met, with the main causes of unmet agendas being explanation of severity, prognosis and test results. Their hypothetical model accounted for only 19% of the total variance in the number of emergent agendas and agendas met or unmet, suggesting that some aspects that were important to the success of the consultation were not captured. However, they carried out an analysis of just psychosocial expectations, and found that higher levels of agendas were met than stated in the pre-consultation questionnaire when doctors picked up on psychosocial problems, allowed the patient more speaking time relative to their own, and engaged in psychological and affective discourse. The data from the current study suggest that expressing agendas is important to promote better consultation outcomes in terms of both health and feeling respected, but that the analysis of the consultation as a separate entity, whether through discourse analysis or analysis of interaction style, is not sufficient for understanding why agendas are not expressed. Additionally, the data show that even when service users provide cues or express agendas, health professionals do not always respond to them, if only to explain their own agendas. Service users need to trust the health professional, and feel respected by them, in order to express their agendas, and a key aspect of respect and trust is feeling listened to and valued within the context of their relationship with the health professional.

### **Individual Personality/Relationship with Health Professional**

This category was expressed by virtually every participant, either in terms of whether the health professional knew them or how well they liked the health professional, and is an important factor in expressed satisfaction with the health consultation experience. Having a long-term relationship was identified as being important by Jonathan, who says of his practice nurse: *“she’s quite OK with me because she’s known me a long time”*, and she also knew his parents. He feels that the practice nurse understands him and he can trust her, and talk to her about anything. When he was very sad after his mother’s death, he told his health facilitator, whom he also knows well. The health facilitator made him an appointment to see a doctor who knew him and understood how close he was to his family. Jonathan has a history of institutional care, psychiatric treatment, and previous episodes where he and his family have felt that he was not respected in medical consultations, so seeing someone who understands him and whom he trusts is essential in order for him to express his agendas and feel that his views will be taken into account. One study (Beach et al., 2006) attempted to measure how well-respected by the doctor patients feel, along with the family doctor’s feelings of respect towards the patient, immediately after the consultation, and relate it to the RAIS analysis of the audio-recorded consultations. The term “respect” was asked about without definition, so agreement on this measure would suggest both a common understanding of what it means and that it is something people can assess in their GP. There was a weak positive correlation between categories at each level of respect, showing that people were aware of how much they were respected by their GP. There was also a significant positive relationship between GP information-giving communication and GP respect for the patient. However, the most significant ( $p < 0.001$ ) finding in the study was the relationship between being known very well by the GP and being respected by them, suggesting that using a patient-centred strategic approach is different from a trusting relationship that is built over time. This is confirmed by a small ( $n=8$ ) phenomenological study of student nurses’ attitudes of respect for service users, where particularly short interactions, such as those in emergency departments, make it difficult to establish a respectful relationship (Clucas & Chapman, 2014). The data from the current study overwhelmingly confirm the importance of knowing and trusting the health professional in a long-term secure relationship.

A good example is Henry’s experience – he sees the doctor on his own if he is unwell, but his sister accompanies him for his health checks with the practice nurse, and he is fine as he just walks in (he does not like waiting) and always sees the nurse he knows. He

nods agreement with Rachel who says it is frightening if it is a new person. She will only go to see the one doctor who she feels can listen to her, talk to her and explain things to her, which none of the others do. Lisbet told me that she was bad-tempered when she went for her health check because she did not know the health professional she saw, or even if they were a doctor or a nurse, and she did not like the experience. Elaine and Penny also expressed a strong preference for seeing the same doctor and felt shy if they saw a different doctor, which prevented them from speaking much in the consultation. Mandy has her health check with one of the practice nurses; she has been with her parents before, but is happy to go without them now, and it seems that she and her parents have developed a trusting relationship with one health professional that allows this. Lindsey, though, identified that her anxiety over seeing doctors is very strong, and influenced by the fact that her father does not like doctors, as well as previous negative experiences and a fear of being examined by a male doctor. She now has one male doctor that she trusts, but she has to see another doctor for regular injections, and she knows that her blood pressure goes up when she sees that doctor, so she has to have her blood pressure taken by the nurse or a lady doctor. Lindsey had a complex and emotionally-charged view of health consultations, but was able to express them within the interview because she had been supported in developing her self-advocacy and assertiveness skills. However, she had not expressed these views to the health professionals.

Edmund feels nervous talking about his health to someone he doesn't know. His sensitivity to new people is exacerbated by having an autistic spectrum disorder, which increases the length of time and mental processing need to habituate to new faces, resulting in a state of hyper-awareness and a reduced ability to attend to and understand other aspects of the environment, including facial expressions (Kleinhans et al., 2009). It also increases sensitivity to touch, thus worsening his anxiety related to his needle phobia, and makes it more difficult for him to process social information. For Edmund, knowing his health professional is essential to allow him to contribute towards the consultation, and to enable him to tolerate blood tests, which are essential because he also has diabetes. Since autism is estimated to affect between 31-35% of people with learning disabilities, compared with approximately 1% of the UK population overall (Brugha et al., 2012), knowing the healthcare professional has an added importance for people with learning disabilities.

This association between seeing the same professional over a long period of time, trusting them and being satisfied with the health consultation was also found in a

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questionnaire study of over 1000 patients, set in primary care in the UK and the United States of America (Baker, Mainous, Gray, & Love, 2003). A pre-consultation Likert-style questionnaire identified that nearly 80% of respondents felt that seeing the same doctor every time they had a health problem was either important or very important, and established the level of trust they had in their doctor, and the level of continuity of care with the doctor they were seeing that day. This was then correlated with a post-consultation Consultation Satisfaction Questionnaire, showing that levels of satisfaction were highest if a patient saw their regular doctor AND they had a high level of trust in their doctor. Trust in the doctor was the single most important predictor of satisfaction, independent of the other variables, and those reporting low trust in their regular doctor were not more satisfied if they saw their regular doctor. So, while seeing the same health professional regularly is very important, it is possible that some service users, particularly if they have lost trust in a particular person, may need an opportunity to discuss that, and build a more trusting relationship, with another health professional.

The question of why interpersonal continuity with the health professional is preferred was explored in more depth in a qualitative study that used interpretative phenomenological analysis of interviews with twelve patients who saw their regular doctor and ten patients who saw an unfamiliar doctor (Frederiksen, Kragstrup, & Dehlholm-Lambertsen, 2009). This study identified that feeling recognised by the doctor, an essential component of satisfaction, involved both being remembered as an individual, and having one's perspective respected, while it was possible for a person to feel humiliated either because the doctor did not remember them as an individual or because the doctor did not validate their views. Even though it was not possible for a doctor to remember a patient the first time, some participants expressed satisfaction with the new doctor because their concerns were listened to, understood, confirmed and accepted – not necessarily in a medical sense, but taken into account as real to the person. This accords with the data from the current study on the importance of liking or trusting the practitioner, as well as the importance of listening. Part of Matt's bad experience with a practice nurse was that she did not seem to "*understand*", while Rachel has now found a doctor she can talk to because the new doctor does "*understand*", and Edmund explains: "*I like anybody as long as they understand me*". This shows that, while interpersonal continuity of healthcare is important, feeling respected in the relationship by having one's self, and the validity of one's own perspective, recognised is essential for a satisfactory consultation experience (Steihaug et al., 2012).



A perception of empathy was found to be positively correlated with patient enablement (See Table 8 for measures used to assess empathy and patient enablement within the consultation) in a small questionnaire study ( $n=136$ ) across five Scottish GP practices, with patient enablement predicting an improved health outcome one month following the consultation (Mercer, Neumann, Wirtz, Fitzpatrick, & Vojt, 2008).

**Table 8: Consultation and relational empathy measure (Mercer et al., 2008)**

How was the doctor at:

1. Making you feel at ease

2. Letting you tell your “story”

3. Really listening

4. Being interested in you as a whole person

5. Fully understanding your concerns

6. Being caring and compassionate

7. Being positive

8. Explaining things clearly

9. Helping you to take control

10. Deciding on a treatment plan with you

Frederiksen, Kragstrup, and Dehlholm-Lambertsen (2010) suggested that the reason why a respectful, recognising health professional is important for a satisfactory patient experience is that all patients are vulnerable and therefore seeking security in an attachment relationship. Thus, they naturally prefer to see someone with whom they already have a relationship unless that relationship has broken down to the point where they no longer trust, or feel secure, with them. Trust, being listened to, being understood, and knowing the health professional well, were key aspects of satisfaction with the consultation in the current study. Being understood is the nearest expressed idea to being empathised with, in terms of meaning, but overall the quality of the relationship was highly important for nearly all of the participants, and was often, but not always, related to knowing the health professional well, or being known by them.

These findings are supported by a systematic review and synthesis of qualitative research into patients’ perspectives of the doctor-patient relationship ( $n=11$ ) (Ridd, Shaw, Lewis, & Salisbury, 2009), where seeing the same doctor and consultation experiences were found to be the key factors in doctor-patient relationships. They caution that retaining an element of patient choice in which doctor consulted is necessary because longevity of care

does not assure depth of relationship. The depth of patient-doctor relationship comprises four main elements: knowledge, trust, loyalty, and regard. It was important to the patient that, not only did they know the doctor, but that the doctor knew them as an individual and knew their medical history. Trust was closely related to feeling that the doctor believed them, with the experience of having their experiences minimised or disregarded engendering a feeling that the doctor did not trust them, which caused a reciprocal feeling of mistrust in the doctor. Trust in a specific doctor was also affected by trust in other doctors, so a previous poor relationship with a doctor could affect security in other doctor-patient relationships (Caris-Verhallen, Kerkstra, & Bensing, 1999). However, listening is more than a sensory awareness: it is part of recognising the person as valued and incorporates understanding, accepting and responding to their concerns, as was shown from a videotaped consultation study of recognising behaviours (Steihaug et al., 2012), a finding supported by the Ridd et al. (2009) review of qualitative research into the patient-doctor relationship. They found listening was associated with having time for the patient (Lings et al., 2003) and was highly valued by service users. This review (Ridd et al., 2009) also identified the following factors as being important to a good relationship:

- Continuity of care, being known by and knowing the doctor (provided they have choice if the relationship is problematic). They need to have experienced care in order to be able to trust them.
- The doctor should appear interested, take the person's views into consideration and explain matters clearly.
- Mutual liking is necessary for a good relationship.
- The views and experiences of important others – family members and friends – will affect the service user's relationship and view of the professional.
- Practice staff attitudes can affect the consultation.
- Loyalty, although patients may choose to see different doctors for different problems, for example, a female doctor for sexual and reproductive health problems.

Many of these findings were replicated in the current study, with the importance of mutual liking, respect and listening suggesting that the needs of people with learning disabilities are similar to those of the rest of the population, although some additional skills and knowledge might be needed to overcome additional communication difficulties. A key finding from the current study, that of the importance to the service user of knowing and

being known by the health professional, was identified, but little research has been carried out in this area (Ridd et al., 2009). This finding was mirrored by a semi-structured interview study of GP patients ( $n=27$ ) in which participants identified the importance of the context of the ongoing relationship with the GP for the quality of the consultation (Gore & Ogden, 1998). However, the conclusion of Ridd et al. (2009), that the longitudinal context of health consultations was a key factor in the effectiveness of communication within a single encounter, was based largely on studies carried out before 2005, and this aspect of the literature seems to have been lost from the current discourse.

This view of the importance of past encounters is supported by data from several participants in the current study who talk about previous bad experiences of not being understood by an “*old-fashioned*” nurse (Matt), or having had intimate examinations without being prepared, which have resulted in pain and bleeding (Penny), or of a needle being “*stuck*” in their abdomen (Lindsey), or doctors not talking to them directly (Rolf, Jonathan, Elaine). This means that health professionals may need to overcome a lack of trust from previous experience before they can start to build a trusting relationship, in which the service user feels secure. Ridd et al. (2009) also found that patients who have developed a trusting relationship with a health professional will overcome other deficits in the practice and some aspects of care if the relationship is satisfactory, which explains why Edmund and other participants who find injections painful and are anxious about blood tests (Penny) and even blood pressure measurement (Lindsey), and who may not like to think about weight loss and other lifestyle changes to improve their health (Matt, Rachel, Jonathan), will return to a health professional whom they trust. Regard – liking the health professional and having a comfortable relationship with them – was a distinct aspect of the depth of relationship that, as with the current study, improved the consultation experience (Ridd et al., 2009). However, many of the participants in the current study identified that their health consultations were much more complex interactions, often involving multiple service providers and triadic consultations.

### **Conclusion – Effects of Emotional Security with the Health Professional on Communication within the Consultation**

This section of the analysis (see table 9 below for a summary of its findings) has concluded that, although studies have found positive associations between person-centredness and patient satisfaction, that is only a partial explanation for better patient outcomes. Listening, responding to cues by the service user, recognising them as a person,

based on a trusting relationship, developed over time, and valuing are all related to person-centredness, but while a health professional may practise in a person-centred way, it takes time to build a trusting relationship. People with learning disabilities are likely to have had negative past experiences of healthcare, and are likely to feel vulnerable due to limited understanding of medical language, and therefore their attempts to contribute to consultation may be in the form of tentative cues. If these are ignored, they will not feel listened to and may feel excluded from the consultation. Indeed, if they do not feel valued in the relationship, they may withdraw from the process completely. A warm relationship, provided it is also an equal one in which the concerns of the service user are jointly explored, is necessary, but not sufficient, to develop trust and emotional security with the health professional. For people with learning disabilities, taking an active part in a health consultation requires effort and confidence, but their involvement cannot be forced by preventing their companion from contributing to the consultation. Rather, trust needs to be built with the person and their carer so that the person can gain self-efficacy and develop their involvement gradually. New situations and new people can be challenging, so continuity of health professionals or, failing that, careful preparation and support, are needed in order to enable people to express their concerns, which can cause them anxiety. Recognising the individual as a person and respecting them is essential for developing a trusting relationship, but this requires time and a genuine liking by the health professional for the service user.

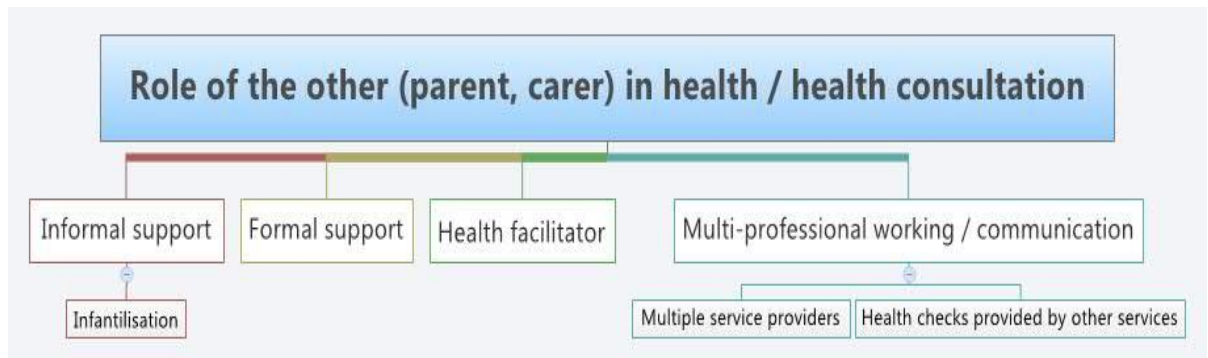
<b>Table 9: Summary of findings on emotional security and communication in health consultation</b>	
<i>Factor Affecting Trust/Emotional Security with Health Professional and Communication in Consultation</i>	<i>Where Evidence Discussed/Derived</i>
Not being listened to meant that the service user's concerns were not addressed. Where tentative cues and prompts are not sensitively responded to, service users feel that they are not listened to and become devalued in the consultation. Health professional's tendency to reach conclusions based on heuristic rules means that it is important to listen to the person, value them and use assessment and diagnostic guidelines.	<i>Listening</i> - Rolf's contributions to his consultation were ignored and the nurse did not look at him; Jonathan has felt ignored by a GP in the past, and by a psychiatrist after his mother died. <i>Cues and prompts in consultation</i> – James' interjection about what protein in his urine meant was ignored.

<b>Table 9: Summary of findings on emotional security and communication in health consultation</b>	
<i>Factor Affecting Trust/Emotional Security with Health Professional and Communication in Consultation</i>	<i>Where Evidence Discussed/Derived</i>
Friendliness	<i>Friendly healthcare professional/Talks to you nicely</i> - Friendliness was helpful where it made the health professional more approachable, but could be used as a barrier to deeper discussion of difficult subjects, and could be disempowering, e.g. unequal use of form of address. Matt's relative view of the friendliness of his psychiatrist and GP affected his openness with them. Jonathan likes his "happy" nurse and Elaine likes a nurse who "talks to you nicely". Friendliness will not overcome mistrust due to previous negative health consultations immediately – time is needed for trust to develop. Penny likes her GP, who talks to her nicely, but is still "shy" with her.
Involvement and inclusion in communication	<i>Involvement in communication/inclusion</i> - Roddy and Kevin both express satisfaction with their limited involvement in their healthcare (Kevin's father represents his needs). No mention of health action planning by service users, suggesting generally low level of involvement in consultation. Where attempted empowerment prevents the relative/parent from representing the person, this can be destructive of the relationship if not sensitively done (Lindsey). Independent involvement can be limited by cognitive ability (Catherine) so empowerment needs a triadic approach. Exclusion from the conversation can be offensive (Catherine/ Jonathan) as well as disempowering. Service users may not attempt to contribute to the conversation if they feel under-confident in the consultation (Lindsey).

<b>Table 9: Summary of findings on emotional security and communication in health consultation</b>	
<i>Factor Affecting Trust/Emotional Security with Health Professional and Communication in Consultation</i>	<i>Where Evidence Discussed/Derived</i>
Ability to express concerns, wants, emotions (agendas) in the consultation	<i>Expressing agendas</i> - Ann was able to express physical problem, but not fears about worsening seizures and trajectory of illness, or wish to see the doctor more frequently. Being understood by health professionals and understanding what they were saying was very important to making service users feel satisfied with the consultation – James, Lindsey, Edmund, Matt. This is why Edmund found the preparation and explanations of the health facilitator before and after consultations helpful, and why Matt did not like seeing an out-of-hours doctor.
The relationship with the health professional	<i>Individual personality/relationship with health professional</i> - Henry and Rachel find seeing new health professionals frightening; Jonathan and Edmund both prefer seeing people who know them and their family well; being understood is important for Matt, Penny, Edmund and Jonathan, part of which is being seen as a person, usually by someone who knows them,



## ***Chapter 4: The Role of the Other in Health Consultation Experiences***



**Figure 2: Role of the other (parent, carer) in health/health consultation**

### **Introduction**

A significant feature in the data from the current study was the role of other people, both within the consultation and in making sense of the experience, as well as in supporting access to care and lifestyle changes. **The effects of other people within the encounter, and on understanding the experience, particularly in relation to multi-professional working were identified in a number of categories that linked to form a major theme: Role of the other (parent, carer) in health / health consultation (see Figure 2 above).** The twin service aims of inclusion in mainstream services and making reasonable adjustments to meet the health needs of people with learning disabilities (Health and Social Care Act, 2012; Improving Health and Lives, Learning Disabilities Observatory, Royal College of General Practitioners, & Royal College of Psychiatrists, 2012) mean that service users often access multiple service providers in order to benefit from specialist expertise and resources. They are often accompanied to consultations in order to ensure satisfactory communication of health information, to promote service users' understanding and involvement in their own healthcare, as well as to facilitate inter-professional communication. These phenomena, which could clearly affect the person's relationship with and trust in their healthcare professional, and their effects on the participants' consultation experiences, are explored below.



## **Multiple Service Providers and Multi-Professional Working/Communication**

Several participants identified a number of different service providers who were involved in their healthcare. For instance, James was seeing an epilepsy specialist, as well as a haematologist and a renal specialist, to monitor and manage the physical effects of his genetic disorder, which had caused his learning disability. Due to the complexity of his health needs, there were difficulties in managing his epilepsy and his kidney function, which meant that his relative had to liaise very closely with James and his specialist to help negotiate the best physical and lifestyle outcomes between them (see *Informal support* for more discussion). Similarly, Lindsey had numerous investigations and procedures, which she found frightening, to find the cause of her abdominal pain. However, she had difficulty in remembering the words to describe her diagnosis, and the explanations and treatment advice she could remember were confused. In addition, because one doctor took her off a drug that triggered side-effects, she lost confidence in the first doctor:

- Lindsey: The last time I'm on these other tablets, it made me go the toilet all the time, and they end up making me dizzy after, and the Doctor 1 stopped me having them [...]*
- H: And was it an antibiotic that didn't suit you?*
- Lindsey: Yes.*
- H: So the Doctor 2 gave you a different antibiotic?*
- Lindsey: That's right, that's what was making me ill all the time [...] they made me worse. Not them tablets. The doctor said "layoff them tablets."*

This discontinuity of health professional may have reduced the opportunity for Lindsey to ask for explanations or gain understanding of the process by which medical decisions were made regarding management of her condition. Her incomplete understanding of her health problems and their management has resulted in her losing confidence in her care and trust in her doctors, which then needs to be regained by any new health professional. The relationship between emotional security and knowing the health professional has been identified within this study as important to the emotional security of participants (Catherine in *Involvement in communication/inclusion*; Jonathan and Matt in *Expressing agendas*; Penny, Elaine, Henry and Mandy in *Individual personality/ relationship with health professional*). When the need for emotional security with one health provider is combined with the need for multiple services and the difficulty in understanding and remembering health explanations, diagnoses, interventions and advice for someone with cognitive impairment, service users with learning disabilities are at risk of withdrawing from

involvement in their own healthcare, due to a sense of exclusion (Thompson, 2007) and loss of control (see Matt's experiences below).

Matt feared that by confiding his mobility problems to his GP, he might trigger concerns about his ability to live independently and have his accommodation needs reassessed, which he did not want:

*Matt: ...the more people, as well, that get involved in things like this, the more complicated it gets. I could have a word with (someone's name), but once you do that then the people all start knowing, and then what they might do is start wondering whether I live, where I live is right for me. I know it's right for me, but they wouldn't. You see, if I told them, oh, I've got a bad leg, they'd say, "well, we need to reassess you then." ...[and you end up with about ten people involved, and they all say different things, and it gets very complicated]...And the only way that we can get, you know, away from that, is for me to see somebody...*

In order to protect his privacy and also to maximise his health outcomes, Matt's family paid for a private physiotherapist. Matt seems to feel that, due to the number of people involved in his health and social life, he has no control and important decisions are made without consideration for his personal preferences. Matt also receives psychiatric care and feels that decisions about him have been made without him. For instance, he was once made to move accommodation at short notice:

*Matt: ....a social worker just knocked on the door and told me that I could not live at that address any more. There was no warning, there was no, you know, pre-warning... He just came in his car, knocked on the door, and told the... The... The people in the house that the authority weren't working with that company any more, and they weren't inspecting it....*

If Matt shows that he is upset, this could be ascribed to his psychiatric disorder, but given that even his family were unable to control something as basic as where he lived, it is not surprising that Matt feels anxious and upset in the face of authority, and the people who represent it. This point also highlights that, while health professionals focus on the health needs of the service users, the health decisions and interventions made will affect social care – a point that is keenly felt by Matt and also affects Owen. At a different level of service delivery, Owen had GP house visits due to his limited mobility, and also had community nurse input to manage his urinary catheter, as well as peripatetic carers to help him with washing and dressing in the morning and evening. Owen felt he had no control over basic daily activities because his carers sometimes arrived very late in the day or put him to bed so early in the evening that he missed his favourite television programmes.

While this care might come under the auspices of social care, Owen, who may have experienced institutional care, sees this as healthcare, and it influences his views and expectations of health consultations and interventions. Discourse on the importance of choice and involvement in healthcare is unlikely to be felt by service users when care delivery organisation overrides personal choice. Additionally, they make associations between all care experiences, so their expectations of health consultations are interpreted through their previous experiences of all care. The greater the complexity of care services, the more likely it is that a negative experience will damage their feelings of involvement with and control of their care experiences.

While most participants would choose to see the same health professional over time (see *Emotional security with a health professional*), this can result in differing standards of care across a practice. Many of the participants, including Ann, James, Matt, Grace, Rachel, Mandy, Lindsey, Mark, Rolf, Tony, Edmund, Catherine and Jonathan, did not see their GP for their annual health check, but saw the practice nurse instead, often knowing the nurse well. However, this means that when service users with learning disabilities are ill, they do not know and are not known by their GP, causing potential communication barriers. As Chauhan et al. (2012) identified from their qualitative interview study of DES health check service providers, having one person as the lead provider of services for people with learning disabilities within a GP practice fosters continuity of care but is “unlikely to lead to change across a practice” (Chauhan et al., 2012, p. 72). Some participants, like Elaine, saw both the doctor and the nurse regularly, but this is unusual and would not be appropriate for people who do not have complex health needs. As we have seen from the chapter on *Trusting relationships and emotional security with the health professional*, not all health professionals are experienced or skilled at person-centred consultations with people with learning disabilities, but negative experiences can have enduring effects on people’s expectations of consultations. Consequently, while health checks may benefit service users with learning disabilities in terms of health outcomes, they may not effect great change in their experience of health consultations outside of the DES. The implications for the many service users with multiple service providers are that their experience may still seem unpredictable and lead to less engagement in their health consultations.

Older service users, such as Catherine, are increasingly using multiple services as their health needs become more complex and long-term (Gates, 2011b). So, Catherine has been admitted to hospital within the previous twelve months, and has experienced

consultations with and interventions by multiple health professionals. Her health facilitator explained that he had attended a multi-professional discharge meeting with her, and she also sees a chiropodist and a dietician, as well as accessing screening services such as mammography, but apart from being able to explain about her mammogram, Catherine seemed quite content to just accept the care that was given to her. Catherine seems to trust health professionals, but her ability to explain or even recall what has happened seems quite limited, suggesting that, while having multiple service providers does not hamper her ability to engage with health professionals, its complexity may reduce her ability to understand her experiences. Several participants in this study used psychiatric services. Jonathan talked about how he had asked his practice nurse why he had not been taken off his atypical antipsychotic medication, and she had explained that he needed to discuss it with his psychiatrist, which he did. He also sees a dietician to help manage his weight, which is affected by his medication, but at his last consultation with the dietician, he felt disapproved of and did not like it. The division of care between different service providers is necessary because of professional accountability, but it is confusing for service users, and Jonathan's experience suggests that some professionals are lacking in expertise in caring for people with learning disabilities and specific mental disorders. Elaine also uses psychiatric services and specialist epilepsy services, and remembers many of her healthcare experiences from childhood and young adulthood. She has a new psychiatrist, whom she calls "*a bit strange*" and when asked why, explains that he weighs her with her shoes on. This highlights the confusion and wariness that a new face and slight changes in procedure can have. Other participants, such as Simon and Roddy, identified that they access specialist psychiatric or epilepsy services, but talked little about them.

Historically, although there is a higher incidence of mental illness, including psychosis, in people with learning disabilities (Bradley & Bolton, 2006; Lindsey, 2002). there has been a lack of awareness in primary healthcare settings of this high risk for co-morbidity (Melville et al., 2005). Additionally, within psychiatric services, mental health professionals and psychiatrists have less expertise in caring for people with the "dual diagnosis" (S. Werner & Stawski, 2012, p. 291) of learning disability and psychiatric disorder. Indeed, service users and their carers identified experiences where they felt physically threatened, bullied and at risk of having property stolen from inpatient stays in mainstream psychiatric hospitals. In addition, their additional needs for support, both physical and communicative, were not supported by the staff (Donner, Mutter, & Scior, 2010). Given the service philosophy of similarity and inclusion in mainstream healthcare

provision (Social Care et al., 2007), people with learning disabilities are more likely to use multiple specialist services (see Edmund in *Health facilitator role*, Jonathan in *Listening* and a carer statement about a participant with epilepsy in *Informal support*). Discussing the provision of a new flexible response service for people whose behaviour challenged the current services and therefore deprived them of opportunities for inclusion, it was identified that up to three other agencies could be involved in working with one person (Carnaby, Roberts, Lang, & Nielsen, 2011). In a concept analysis paper, Leyin (2011) argued that it would be helpful for the psychology services to make an initial personal contact to improve access to their services as part of an Improving Access to Psychological Therapies (IAPT) initiative. He also identifies that time limitations and diagnostic overshadowing may prevent identification of need and referral by primary health services. However, he goes on to say that, while some people with learning disabilities may not benefit from the services due to their inability to express their feelings and understand and consent to the process:

“For those outside IAPT, using the terminology familiar to IAPT would increase the likelihood of developing dialogue between the IAPT service and the specialist learning disability service. This would extend not only to interventions per se but also to the way in which the service is organised”.

(Leyin, 2011, p. 34)

This suggests a need for professional support in enabling service users to access some specialist services, even when they are supposedly improving access. Current commissioning guidelines require clinical commissioning groups to ensure the provision of health facilitators to support health action planning and annual health checks, which are now regarded as an essential reasonable adjustment to meet the health needs of people with learning disabilities (Disability Rights Commission, 2006). They also require additional provision in the form of health facilitators and/or learning disability liaison nurses to work with acute services to ensure that the needs of patients who have learning disabilities are met with reasonable adjustments and that discrimination is avoided. Additionally, mental healthcare services are required to provide care for people with learning disabilities and psychiatric disorder (Improving Health and Lives: Learning Disabilities Observatory et al., 2012). This drive to include people with learning disabilities in mainstream services, while important in terms of promoting equity and diversity throughout healthcare provision, could have the effect of marginalising the service user with learning disabilities within the specialist service (see *Psychosocial healthcare/needs*), putting the onus on specialist service providers to make reasonable adjustments to meet the needs of people with learning

disabilities within their service (Disability Rights Commission, 2006). However, some service users rely on informal support from friends or relatives.

## Informal Support

For many participants, the relationship with the health professional, and therefore their experience of health consultations, involved the presence or influence of at least one other person, whether that was a family member, formal carer or health facilitator. Before attending health consultations, participants with informal support were likely to discuss their health needs with that person. James and Edmund both look to a parent for help and advice before seeking medical assistance. Informal carers often provide a sense of security and a feeling of social support:

*James: Yeah, I am well looked after. Me Mum, ... Mum looks after me, you know if I'm not well my mum is always on the other line, on the phone*

Edmund explained that his illness sometimes causes problems in his genital area but, because his father also has diabetes, he can ask his father for advice, especially at the weekend when it is difficult to access his health facilitator. His father also advises him on his medication and collects it from the pharmacy. As identified in the “Agendas not expressed” category, Mark’s mother does not pursue his concern about headaches with the health professional, suggesting that relatives may act to prioritise health concerns and reduce the number of consultations made. This is supported by a case record and interview study to investigate why consultation rates for adults with learning disabilities are lower than those for adults in the same age group with long-term conditions, and why some consult more than others (Turk, Kerry, Corney, Rowlands, & Khattran, 2010). The study involved 187 adults with learning disabilities, 27 being interviewed independently, 63 interviewed with a carer and, in the case of the remaining participants, only the carer was interviewed. Key factors such as type of support, co-morbidity, medication, pain self-report, transport, ease of access to GP practice and psychiatric illness were related to case note records to identify significant relationships to frequency of attendance. Overall the consultation rate was just over three times a year for women, and just over twice a year for men, lower than commensurate rates in the general population. However, people who lived with family were less likely to attend than people with paid carers, while people who lived independently or did not have anyone to tell about pain had the lowest attendance rate, with over a fifth not seeing a health professional in the previous year. So, relatives may not

facilitate as much access to health consultations as paid carers, possibly because they make decisions about whether the person's concerns justify a consultation.

There was little suggestion in the current study that service users were unwilling to discuss health issues with relatives (with the exception of one young woman who now received health facilitator support instead). There is some evidence that their role as social support may reduce the need to see a health professional. This supports the findings of Turk et al. (2010) that people without any support may not recognise a need for healthcare, and may have difficulties in accessing health services. People who have a close long-term relationship with service users are more likely to observe changes in their health, but they are less likely to access health services if they perceive problems to be trivial or interventions (such as cervical screening) to be unnecessary (Alborz, McNally, & Glendinning, 2005). Since most carers think that service users are poorly treated in health consultations (BILD, Department of Health, & Mencap, 2013) this could also discourage attendance for consultations. Although carers (paid and unpaid) have been found to have control of attendance for health appointments and health choices for people with learning disabilities, they have also identified that if a service user does not want to attend an appointment, they will usually defer to the service user's wishes (Ferguson, Jarrett, & Terras, 2011). This highlights the importance of the service user's experience of health consultations (and their companion's perceptions of this) in choosing whether to attend future appointments. In addition to the mechanism identified by Thompson (2007) by which service users "opt out" of health consultations, negative evaluation of the health consultation by the carer could contribute to poorer uptake of healthcare services. It also highlights the importance of including the carer in the consultation, to promote the health knowledge and decision-making ability of both carer and service user. In an emergency, the carer is a source of practical and emotional support when others may not understand exactly what the service user is telling them, as with Ann's brother:

*Ann: I said to him [...] come with me to the (name of hospital)... Before it squeals... 'ore it squeals [...] in – I said I can feel the pain there*

Another role that the relative sometimes undertakes is to prepare the service user in advance so that they can express their agendas and so that they are prepared for any procedures:

*H: Or would you have liked to tell her what was your problem so she could tell you what help you could have?*

*James: Well, sometimes I can't... well sometimes I can't think which one it is because with me learning difficulties, you know, it's very hard to think, but erm,*  
*Relative: But I always give you a rundown before you go don't I?*  
*James: You do, always give me a rundown yeah, before you have anything, just to tell you why you're having it*

This accords with the finding by Perry et al. (2013), in which people who lived with support had their health checks explained in more detail and were more prepared for them.

Relatives also provide transport and assistance with accessing health services:

*Friend: ...(quietly to Henry) does. (Indistinguishable) take you to the hospital, does she?*  
*Henry: Yeah.*  
*Friend: Oh, his sister takes him, at least on his answering form*  
*Henry: Yeah, the sister comes with me...*

Accompanying someone to health consultations sometimes requires two relatives, particularly where parking is difficult:

*H: And, did you go on your own? (Pause) or did you go with someone in your family, or a carer?*  
*Mark: Went with me mum... Dad took us there.*  
*H: You dad took you?*  
*Mark: Yeah.*  
*H: And you went in with your mum?*  
*Mark: Yeah.*

Indeed, the stress of parking for the relative can affect the service user's experience, and may also be an indicator of how stressful health consultations can be:

*Tony: (indistinguishable) I hate car parks [...]What a nightmare [...] No room*  
*H: No room to park?*  
*Tony: No*  
*H: So that irritates you, does it? [...]*  
*Tony: Yeah... Got in a bad...*

In their large focus group study (n=102) (see Table 10 for discussion topics used to explore the service user's perspective) of the experience of primary care for people with learning disabilities, Perry et al. (2013) found that those people who required help to get to the GP practice did not have as much difficulty accessing healthcare because of not needing to get buses or taxis.

Table 10: Focus group discussion topics	
	(Perry et al., 2013, p. 3)
<i>Study 1</i> 'Getting to see the doctor', 'Communication issues',	



'Being healthy' 'What would make things better?'
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<i>Study 2</i>
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'Before the health check'
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'During the health check'
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'What would make things better?'
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This is a procedural issue of access. However, the difficulty that Tony's father has in parking for him to see the doctor (see extract above) creates a psychological tension that affects Tony and is associated with his health consultation. Both Rachel and Henry felt that parking for medical appointments took too long and that having to pay for it when they both had disabled badges was unfair. While physical and economic factors can be barriers to accessing healthcare, psychological factors can reduce motivation to attend consultations (Thompson, 2007) or make them less effective by creating negative emotions related to the experience (see Rachel's experience of lifestyle advice later in *Informal support*). Many of the barriers to access, such as difficulty in parking and parking payments, can add an additional layer of stress for the relative or carer, which may affect the way the service user experiences the consultation. Additionally, their dependence on relatives for transport to health consultations (Tony went with his mother and father) could reinforce perceptions of them as dependent and therefore as having less to contribute to the process, or being less likely to want privacy for some part of the consultation.

Relatives were also used to provide family medical history and immunisation history within the consultation. They also liaised with various health and social care professionals, often becoming experts in the service user's health needs:

*Relative: 'cos he has blood tests regularly because of his, he is anaemic you see. He'd been referred to a haematologist, you see, to see what they can do, because at the moment it's 10.2, ermm, and of course, for a man, it should be up to 17, really, but, ermm, so were going to see a haematologist, but this has been (pause) it's 'cos his kidneys don't work fully. His kidneys under-function, so, and yet the tablets are necessary to control the epilepsy and blood pressure, so it's a Catch-22 really. Ermm, but, and they don't - this combination that we've got now for the epilepsy, it took years to get it, absolute years and the specialist won't, I've been to two, to ask them if they introduce it, and they won't, they say it's too risky. So, okay, we'll leave that, but it does affect areas as well, and of course the kidney with the tumours in. So, ermm, but his medication isn't changed a lot but it is changed to see if it ermm helps, and we monitor, and it seems to be working for you doesn't it?*

The need to communicate in medical language limits the ability of the service user to contribute to the conversation, and requires the relative to inhabit the world of the

health professional in order to represent the interests of the service user. The importance of this role means that the relative occupies a key position within the consultation, particularly where health needs are complex, making it difficult for the service user to see the health professional without the relative's attendance:

Lindsey: *No, I... Last time we went the doctor's, me Mum used to take me...*  
H: *Yeah.*  
Lindsey: *... And then... After me... When I hadn't got me mum, I got a carer, and now me, yeah... One of my family, my auntie normally takes me now.*  
H: *Hmmm.*  
Lindsey: *Because they have to now.*

This could inhibit the person's ability to raise agendas that might be difficult to discuss in front of them, for example, sexual health. There is some evidence from the current study to suggest that this is the case, for example when James' mother denies that he is sexually active (see *Explanations and understanding* and *Anxiety, embarrassment and gender related to health encounters* for further discussion). As we have seen previously, where Mark thought his mother did not express his fears that his headaches could be a symptom of a serious brain disease, this can lead to agendas not being expressed if the relative does not think it appropriate. While the relative may be acting to present themselves and the service user as credible, and therefore more likely to receive appropriate care (see *Embarrassment, feeling shy, labels within learning disability, presentation of self, credibility*), this may cause anxiety for the service user.

The relative may also use their observations to confirm or add to the service user's self-reporting of symptoms:

Rachel: *When I go, and Errr (name of carer) is... When, when, when (name of carer) is with me, she... She... Talks to them, and my sister, and they tell them what's wrong with me, and then I... And I... I tell them, then...*

In the extract below, taken from a consultation, the relative answers questions about symptoms as if she were the service user:

HCP: *Do you ever get any swollen ankles?*  
Relative: *Well, occasionally. But not, you know, sort of, erm,.....*  
HCP: *OK. Is that at the end of the day? When you've been up on your feet all day?*  
Relative: *You notice them more at night*  
HCP: *They're not swollen now, no?*  
Service User: *No*  
HCP: *Oh no, you've got lovely ankles. I can see that there. Beautiful. Alright. Lovely.*

In this consultation, although the health professional nominally addresses the service user, the majority of the conversation was between the relative and the health professional, except where the service user was being examined, or lifestyle advice was given. This is echoed in Perry et al.'s (2013) study, where service user focus groups identified that people accompanying them needed to limit their support role to what the person with the learning disability wanted. As found by Ellingson (2002) in her observational grounded theory study of older people attending an oncology clinic with companions:

“...companions who are highly active in interactions provide important information and perspectives, but they also may marginalize patients’ views.”

(Ellingson, 2002, p. 378)

However, it is not necessarily the carer’s choice to play such a visible role in the consultation, simply an extension of their role in communicating their knowledge of the service user and their needs to the health professional. As Dinsmore (2012) found from interviewing five people with learning disabilities and ten carers about their most recent hospital inpatient experience, nearly all participants felt that the carer’s knowledge of the person was rarely solicited and often ignored or dismissed, despite its importance to their health outcomes. When interviewed by Ali et al. (2013), carers also felt that health professionals did not share information with them and were disapproving of their attendance in consultations. Thus, the relationship between the service user, the carer and the health professional is important in terms of both the advocacy role of the carer, and the trust of the health professional by the service user.

Some service users give examples where the health professional does not attempt to include them, relying solely on their relative, which, as well as limiting the possibility of them expressing their agendas, also suggests that they feel devalued as a person:

*Rachel: Nobody ever just asks what... What's the problem with you?*

*Grace: They ask... They ask who's with you, normally...*

*Rachel: Yeah.*

*Grace: You don't... You don't, some... So a lot of the time, you don't really get chance to, sort of, ask questions and talk and... Some... 'cos other people do all the talking, you're just sat there.*

This feeling of being excluded, and therefore devalued, is just as important when the person has limited communication skills (sometimes related to medication), and, as the extract below shows, can leave a lasting impression:

*Elaine: Well the doctor speaks to...used to speak to my mum and I used to walk out and get upset because I wanted the doctor to talk to me and involved me a little bit. Even though at one point I did have little communication but I wanted the doctor to talk to me as well and ask me how I feel and ask me if I was OK, not just talk to my mum.*

However, not all service users want to take part in the consultation:

*Carer: What do the doctors usually say to you when you go for your annual check-up?*  
*Lisbet: Who have I brought?[...]*  
*Carer: Do they talk to you?*  
*Lisbet: No, my mum.*  
*H: Do you like that?*  
*Lisbet: Mmmm.*  
*H: You don't want them to talk to you?*  
*Lisbet: No, to my mum.*  
*H: And do you talk to your mum about what you want her to ask the doctor?*  
*Lisbet: Mmmm.*  
*H: And does your mum explain to you what the doctor says?*  
*Lisbet: Mmmm*  
*H: And you're happy with that?*  
*Lisbet: Mmmm.*

As illustrated above, even if they are not very vocal in the consultation, service users do discuss their health consultations with their carers. Where cancer patients are passive in consultations, they still actively listen to the interaction (Cordella, 2011), so it is likely that service users with learning disabilities do, but need help to understand the full meaning of the conversation afterwards. The carer and health professional have the dual role of communicating with each other for the benefit of the service user. Relatives may welcome or accept the role of spokesperson, but in the current study they generally want the service user to be included in the consultation. Participants with relatives regularly referred to their family member being upset if the health professional did not include the service user in the consultation:

*Lindsey: Well, this... I had a first doctor who was very nice to me... His name was Dr (surname) that I had, and this one's more better..., than Dr (surname).... He always talks to me and then when he talks to me, he speaks out clear and then, if everything is clear, he turns to me mum, then he talks to me as well as me mum [...] but this Dr (surname), he won't do that.*  
*H: Right.*

*Lindsey: He always tells... He always looks at me, but not the next person.  
H: How does that make you feel?  
Lindsey: It f... I don't know... I feel... Not relaxed at all... I don't know why... Some doctors are fine, some are not... That's why I can't... No wonder me dad hates it... me dad hates doctors[.....] he can't trust doctors [....] I think he's right, in a way [....] some of them are not... Some of them are rude... Always talks to me, and not... But not someone else...*

It is clear from the above extract that the experiences of the service user and the relative can be co-constructed, affecting the meaning that they take from it, and their satisfaction with the experience. This means that it is necessary for the health professional to build a good relationship with the relative in order to develop one with the service user. Video analysis of 96 parent-physician relationships in child consultations (Cox, Smith, Brown, & Fitzpatrick, 2008) identified that showing hurried or rushed behaviour was negatively associated with the doctor understanding or liking the parent, while friendly behaviour by the doctor was related to liking the parent. Doctors' interest, engagement and empathy were all related to understanding the parent, while anger or irritation related to a lack of understanding. The data from this study show that service users and their companions are aware of situations when the health professional does not like them or lacks understanding of the carer's perspective, and that this can harm the relationship with the service user. This, aligned with previous findings that carers are less likely to pursue healthcare if they feel that the service user will not be taken seriously or will not gain benefit from it (Alborz et al., 2005), means that the health professional-informal carer relationship is a crucial element in the health professional-service user relationship. Despite this, a survey of 75 people with learning disabilities and 191 family members, asking them about their experiences of healthcare over the previous twelve months (BILD et al., 2013), found that 46% of respondents with learning disabilities felt that healthcare staff were very caring towards them compared to only 14% of respondents in the family survey who felt healthcare staff were very caring towards them (family members and family carers). Families felt that healthcare staff were more caring towards the person with learning disabilities than towards their family members (Department of Health, 2013a), which could ultimately affect the service user's trust in the health professionals.

Even though Lindsey has earlier explained that she does not like answering questions within the health consultation, and she needs help in understanding what the doctor says, especially if they don't "*speak clearly*", she still likes to be included in terms of eye contact and being spoken to, along with her relative (whom she does not want

excluded). She is able to discriminate between doctors who make her feel relaxed and included, and those who do not, but her father's feeling of mistrust towards doctors makes her wary of them also. Rolf had a similar experience, when his mother was upset by a lack of eye contact from the doctor (possibly related to computer use – see section on *Communication barriers*):

Rolf:        *Me and my dad.*  
H:            *You and your dad? And does he go in with you to talk to the doctor? (Nodded head) so [...]... and did you talk about that to your doctor after, in the health checks?*  
Rolf:        *I went with my parents there... They wouldn't say anything to me [...]*  
Rolf:        *Never talk to them... (Indistinguishable).*  
H:            *Does she talk to you, or does she talk to your mum?*  
Rolf:        *Me mum [...] My mum wasn't very happy about it [...]*  
H:            *Why not?*  
Rolf:        *She didn't talk to my face. (Indistinguishable).*  
H:            *She-she-she thinks she should have talked to you?*  
Rolf:        *Yeah, and talked to her face [...] she was very upset.*

Again, the way the health professional interacted with the service user was important to the relative, Rolf's mother, whose response to the situation affected the way Rolf felt about it. Other studies have focused on the patient's feelings about being marginalised within the consultation (Cahill & Papageorgiou, 2007; Ellingson, 2002; Perry et al, 2013), but the current study has identified that health professionals who do not include the service user in the consultation, and do not show that they respect them through positive engagement, are also likely to alienate the service user's relative.

Although it is possible for relatives, sometimes, to dominate the interaction, they are more likely to promote the personhood of the service user within the consultation. This is echoed in an interview study of factors that damaged or promoted good communication between nursing home staff and relatives ( $n = 103$ ), with the example of staff not interacting with residents given as a factor that negatively affected the feelings of relatives towards the nursing home (Majerovitz, Mollott, & Rudder, 2009). In their review of the literature on triadic consultations in children's primary care consultations, Cahill and Papageorgiou (2007) found that children were mainly involved in the social talk aspect of consultations and older children often felt marginalised, although the parents' management of the conversation was generally aimed at protecting the child and promoting their interests. However, this manifested as a dyadic partnership between health professional and parent, with the child becoming subordinate in, rather than central to, the interaction. Interestingly, when the health professional supported child

involvement, their involvement in the interaction was more likely to occur, and even more likely if the parent supported it as well. A review of adult triadic consultations with unpaid carers/companions (Laidsaar-Powell et al., 2013) identified that health professionals were concerned about possible dominance of the consultation by the companion, but there is little evidence, in the current study or the literature, to show that companions exceed the adult service user's desired level of support. Communication in health consultations for people with learning disabilities is often discussed in terms of dyadic relationship skills, with some discussion of how to overcome confidentiality issues when a third person is involved, or in terms of family care where a child is involved (Broussine & Scarborough, 2012). However, the possible issues that are raised by compassionate infantilisation (through under-involvement in the health consultation), possibly due to a history of the marginalisation of people with learning disabilities within the health service, suggest that this aspect of consultations needs more exploration for the guidance of health professionals. One service user in the current study (Elaine) suggested that she had wanted a more active role in her early adulthood, but the combination of medication, mental health diagnosis, failure to promote involvement by her GP at the time, and continuation of the child role made this difficult.

The current study shows that compassionate infantilisation by parents of adults with learning disabilities is perceived to be less of a problem than it seems to be with children in the wider population (Cahill & Papageorgiou, 2007), but it can occur, particularly where the health professional does not promote the autonomy of the service user, or where the parent feels a need to advocate for better healthcare for the person. In the current study, I observed a health consultation where the health professional was friendly, thorough and helpful, although inclusion of the service user tended to be mostly about gaining co-operation and explaining key aspects of self-care. The parent was clearly aware of the importance of relationship-building with the health professional, and the service user's voice was only partly heard, with some cues for information and understanding being ignored. However, when I visited the service user and parent in their own home, the relationship between them was much more equal, and the service user was clearly self-confident and, apart from some memory lapses, was able to give well-reasoned opinions and express his views. This echoes the conclusions of Barry et al. (2000):

“Outside consultations patients are more fully present: as socially and contextually situated, thinking, feeling people, with their own ideas on their

medical condition and opinions and possible criticisms of medical treatments”

(Barry et al., 2000, pp. 1249-1250)

Where the parent and the service user have a good relationship with the health professional and trust them, it becomes easier, sometimes, for service users to attend some appointments independently, like Mandy: *“I have been with my parents, sometimes, but last time I went on my own, and it was okay”*; or with a different person (Elaine).

Informal support can also help by reducing anxiety, particularly related to health and health matters:

Jonathan: *I do worry about things but...I'm going out with [...] next door.*  
H: *[...]And does that make you feel better?*  
Jonathan: *Yeah.*  
H: *Yeah. What does she say?*  
Jonathan: *The right things.*

When Rachel became upset following being told she was overweight by the practice nurse her boyfriend helped her to feel better:

Rachel: *I didn't... I... I just... I didn't like myself, the way I was [...] In size... And that's how I felt.*  
H: *In what... In what way didn't you like yourself?*  
Rachel: *The way you was when they're looking at you... You know when you're looking in the mirror...*  
H: *... Aaaah...*  
Rachel: *... And you're... And me boyfriend says: "you shouldn't do that, it's here, what counts, in your heart." Which is true, innit?*  
H: *It is, yes.*

Friends can be good role models and give advice on health lifestyle, as with Edmund, whose friend helped him with weight loss:

Edmund: *'Cause seeing one of my friends, how much he's made a difference is amazing.*  
H: *Wow!*  
Edmund: *He was a lot bigger than me. ....'Il tell you that and now it's like what? You wouldn't think it was him!*  
H: *No?*  
Edmund: *And now he's....he doesn't...he's...he's even been discharged from the doctors now.*  
H: *Wow! Amazing. So...*  
Edmund: *And he gives me a few tips.*  
H: *Right.*  
Edmund: *Which is really helpful.*



Service users in the current study valued the role of their unpaid companion for providing logistical support, information and communication support before, during and after the consultation, promotion of their personhood (both in and out of the consultation) and advocacy of their needs, as well as for their health, social and emotional support and facilitation of healthy lifestyle choices. This is echoed in Laidsaar-Powell et al.'s (2013) review of adult patients in a wide variety of settings, where companion presence was associated with improved understanding of the consultation, a better quality and quantity of information exchanged with the doctor and greater feeling of comfort and freedom of expression for service users within the consultation. From her discourse analysis of nine triadic encounters in a Chilean oncology clinic, Cordella (2011) identified seven different roles adopted by the patient's companion (see Table 11).

<b>Table 11: Seven roles of the companion</b>	
	(Cordella, 2011)
• Secretary	
• Carer	
• Financial assistant	
• Health advisor	
• Social communicator	
• Reporter	
• Partner	

The data from the current study show that all of these roles have their equivalent in the unpaid companion role for service users with a disability, but that the companion also has the role of *maintaining the personhood of the service user* in the medical encounter, that is, presenting them as a whole person with feelings and individuality, as well as maintaining the person's sense of self in the face of medical language communication and exclusion of the service user from the interaction. My analysis shows this as a distinct role from Cordella's (2011) social communicator, because it is not only about introducing social elements of the person's life into the consultation, it is actively demonstrating and promoting engagement with the service user as a person in their own right, from encouraging the health professional to interact with them, up to humanising the advice given in the consultation to promote concordance and enhance the relationship with the health professional. This role can sometimes conflict with the other roles, particularly those of reporting on symptoms and developing the carer's relationship with the health

professional, which often rely on the common use of medical language and quick informational responses.

The role of *personhood promotion* could also conflict with the parent role in situations where autonomous choices by the service user could seem potentially harmful. The review by Laidsaar-Powell et al. (2013) also identified that a companion's presence in generic health consultations could inhibit discussion of intimate subjects, such as sexual health, and there was some evidence of this in the current study where despite the service user identifying the existence of a girlfriend in the past, the parent told the health professional that he had not been sexually active, preventing exploration of any sexual or reproductive health needs. Lindsey was unable to discuss "*personal*" issues with her father, but needed someone with her because of hearing and understanding difficulties, and attended assertiveness and self-advocacy groups in order to address this. In Perry et al.'s (2013) focus group study of service users' health check experiences, there were some participants who preferred to attend health checks on their own, while others simply wanted to be able to control how big a role their companion played in the consultation. In the current study, however, the service users seemed to identify very closely with their informal carers, and family members were generally seen as allies in the health consultation. This difference in findings may be due to the carers in Perry et al.'s (2013) study including paid carers. The role of paid carers will be explored in the *Formal support* section below.

## Formal Support

As seen previously with Daniel (*Expressing agendas*) and Rachel (*Involvement in communication/ inclusion*), when service users are accompanied by paid carers, health professionals sometimes communicate almost exclusively with the carer, who answers questions on behalf of the service user, but the service user may not want this:

H: Does the doctor ask you anything at all?  
Daniel: No, never. (Indistinguishable). Thumbs up, thumbs up [...]  
H: ... You gave him a thumbs up [...] When he asked you how you were...  
Daniel: Yeah.  
H: So did he you talk to you?  
Daniel: Yeah, yeah, yeah.  
H: Did he ask you the questions?  
Daniel: Errr... No, he asked the carer [...]  
H: And what did the carer do? Did the carer answer the questions?  
Daniel: yeah [...]

H: *Did you understand what they were saying?*  
Daniel: *Yeah.*  
H: *Did you say anything?*  
Daniel: *No.*  
H: *Why not?*  
Daniel: *Too shy.*

This is supported by Perry et al.'s (2013) service user focus group study, where paid carers were seen to talk too much in the consultation. However, adolescence and young adulthood, when intimate and personal matters can be difficult to negotiate, can make parental involvement in consultations problematic, even when the parents are acting in the best interests of the service user. Elaine explained that her mother did not always allow her to say what she wanted to in consultations and went on:

Elaine: *Well I didn't have...er...my carers when I was at home. My mum looked after me instead [...] and she kept telling me she was like my carer [...] but I said you're not a carer but she says I'm like your carer.*

Elaine now chooses to attend health consultations with her paid carers, with the aid of her health facilitator, which supports the findings of Laidsaar-Powell et al. (2013) identifying that patients generally may feel embarrassed discussing subjects of an intimate nature in front of companions. This suggests that the presence of a paid carer, rather than a parent, may lessen this as an issue for young adults with learning disabilities. However, Wullink, Veldhuijzen, Lantman-de Valk, Metsemakers, & Dinant (2009) in their focus group study ( $n=12$ ) found that service users sometimes needed the opportunity for privacy with the doctor, so within triadic consultations it is helpful for the service user to be given the opportunity to speak with the health professional alone at some point.

So, being supported by a paid carer can be perceived as helpful by the service user, particularly where they feel a need for independence and privacy. Nonetheless, even paid carers can affect the privacy of the service user (Ziviani et al., 2004), suggesting a need for some private time with the health professional. However, there can be disadvantages to being supported by paid carers in a consultation. Ann explained that she has frequent epileptic seizures, a health problem that she thinks is deteriorating, sometimes requiring emergency attendance at her GP practice. The practice is across the road from her, but she is taken in a taxi with two carers. She has a number of different carers, and when she went for her health check, the practice nurse asked the carers to keep a record of her seizures.

Ann: *When you have a file out [...] And write it down for the doctors*

- H: Right, so she wanted [carer's name] to keep a record of when you had your seizures?*
- Ann: Yeah, that's it! [...]*
- H: Yes, so that was part of her health check-up of you ...*
- Ann: ... Yeah...*
- H: ... Making sure that the people who look after you make a record of your seizures?*
- Ann: Yeah*

For Ann, the role of the carer as health advisor (Cordella, 2011) could not be achieved on an individual level because Ann lives in a group home, where paid carers provide care over 24 hours. From Ann's account, she is accompanied to health consultations by a number of different carers, so there is no single "expert" able to act as health advisor on her behalf. Consequently, the practice nurse was unable to identify patterns or frequency of seizures to assess Ann's healthcare needs and evaluate care related to her epilepsy, so requested that records are kept of seizures for future health checks. Perry et al.'s (2013) service user study also found that the carer who accompanied the person to their health check needed to know them well, with GPs interviewed in Australia expressing the importance of the carer having detailed knowledge of the health needs of the person, both from keeping records and from observation, in order to be helpful in the consultation (Ziviani et al., 2004). This perception that Ann has taken from her health check of carers not fulfilling the health advisor role is supported by a service-user study into annual health checks:

"One doctor said that health checks were not useful because carers did not do a good job – sometimes they did not know anything about the people they brought for a health check. Sometimes, they did not help people live a healthy life."

(Michell, 2012, p. 155)

Commissioners of learning disability services have also suggested that commissioned social care services have not always been able to deliver the level of support needed to care for people with complex health needs (Gates, 2011a), while their educational needs in relation to cancer risk and prevention have also been highlighted (Wyatt & Talbot, 2013). This suggests that in order to gain value in the health consultation, and thereby have the opportunity to maintain the personhood of the service user and advocate on their behalf, companions must also be able to act as health advisors. Where relatives, particularly parents, have taken on this role, it gives them value within the

consultation which, allied to their next-of-kin role, empowers them to advocate on behalf of the service user. Where paid carers accompany the service user, unless they have sufficient knowledge of the person, their medical history and health needs, their value within the consultation will be diminished and with it their efficacy as an advocate on behalf of the service user.

When Rachel explained that she had been upset by the practice nurse telling her that she was overweight and at risk of cardiac problems, she had been accompanied by a paid carer, but became so distressed that they had to telephone her relative to talk to Rachel. I asked Rachel what she would do if she was sent an appointment to see that nurse again:

*Rachel: I wouldn't go to her; I'd say no.*

*H: What would you do if you got an appointment through the post?*

*Rachel: I'd probably... (Carer's name) I'll come with me. I don't know, d'you?*

*H: Hmmm, yeah. Would you tell (carer's name), that you were unhappy about the last time?*

*Rachel: I'd ...saw (relative) and she 'phoned (another relative) up and she said "she's enough worries on her plate without her saying it!"*

Although Rachel lives with paid carers, it is her relatives who can intervene on her behalf when she is unhappy with her health consultation. For both Ann and Rachel, the paid carer has an unequal relationship with the doctor, reducing their effectiveness as both health advisor and advocate. Catherine, however, has a different experience. She lives in supported accommodation with two other service users, and has previously attended health checks alone, but carers now accompany her so that they can remember the advice she has been given and incorporate it into the support plan they record for her. This includes dietary advice, appointments that need making or attending, and medication changes. So, while Catherine is relatively independent, her support carers have instigated a record-keeping and planning approach. This will make their health advisor role in consultations more effective, and facilitate Catherine in responding to advice (for example, with food shopping, menu planning and exercise opportunities), and making and attending future health consultations and referrals. This is significant because an interview study (Ferguson et al., 2011) of adults with learning disabilities ( $n=4$ ) and their carers ( $n$  paid carers=11 out of 13) found that carers mostly made decisions about attendance for health consultations for or with the service user. Additionally, carers reported that they either made food choices for service users or presented them with preferred options. Thus, health promotion in the consultation needs to be aimed at both service user and carer if it is to be

effective. Some participants were able to access the health facilitator, and identified a number of different ways in which the health facilitator affected health consultations.

## Health Facilitator Role

As we have seen, the lack of continuity and reduced power within the health consultation for the paid carer can make it a less effective experience for the service user. An alternative or enhancement to being accompanied by a carer can be provided by a health professional who knows them well and can support them in health consultations. Some of the participants identified this intervention by the health facilitator (a qualified nurse, sometimes with learning disabilities or adult nursing qualification, sometimes both) as an aspect of their consultation experience (in primary and secondary care), and as an aspect of communication between them, their health professionals and carers:

*Edmund: ....It's really helped. They've been around me when I've needed it which has been brilliant really. I wouldn't be where I am now if they wouldn't have helped me, if you understand what I mean? [...] the sad thing is I can't speak to my family about things like that. I know it sounds quite...unusual. I don't feel very comfortable speaking to my family about it.*

Edmund was able to talk to his health facilitator when serious family problems were making him sad. The health facilitator arranged a GP appointment for him, with a friendly GP whom he knew, which resulted in him being prescribed anti-depressants, which he found helpful. This echoes the views stated by service commissioners that specialist learning disability nurses are important in promoting the needs of service users in healthcare (Gates, 2011a), and suggested that even if paid carers attend consultations with service users, the health facilitator can increase their effectiveness as advocate and health advisor. Service users also wanted specialist learning disability nurses to provide services such as sexual healthcare and health assessment, and to take blood, give injections and provide expert advice on challenging behaviour (Gates, 2011b). Edmund accesses a wide variety of health, social and learning disability services, but by having one person who helps him to understand where he can access help and what sort of help is available, and to integrate his care through inter-professional communication, his relationship with the health professionals is more straightforward. This is particularly helpful as ill health is affecting his usual family support, so the health facilitator helps him to prepare for health consultations and supports him in the consultation:

*Edmund: Sometimes there's a thing the doctor says I don't quite understand and he*

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*could [...] mention to the doctor maybe to explain it in a different way to me [...] He mainly just comes with me just to make sure I understand everything really [...] the more he's gone with me and the way the doctor's explained things to me, it's helping me learn a bit really and to understand what they're saying.*

Edmund explains that the doctor and nurse will talk to him first, but also talk to the health facilitator, who then chats briefly with the health professional after the consultation. On the drive home, they then discuss the consultation to help Edmund to understand the outcomes of the consultation. He has found this helpful as it has enabled him to gain control over his diabetes through changing his diet and exercise and managing his insulin injections himself.

Lindsey's health check was actually carried out by a health facilitator, showing that there are different models of health facilitation, but with the adoption of the Direct Enhanced Service (DES) for people with learning disabilities, health facilitators generally aim to support GP practices, rather than replace them in the provision of health checks. However, Lindsey preferred it done by the health facilitator: *"if they do it, I'd always go to her"*. Rolf had also had his health check carried out by the health facilitator two or three years previously but said he hadn't had one since, that is, since the DES was introduced to the area.

The health facilitator also supported participants with hospital appointments:

*H: ...Do you see hospital doctors very often?*  
*Edmund: No I don't actually but I think that's something that we are...that me and [the health facilitator] are gonna be working on very soon*

and by liaising with hospital personnel when service users were admitted to hospital. Catherine had major surgery, and her health facilitator visited her and attended a pre-discharge meeting with her to ensure that she had all the support she needed on discharge and understood the care needed. The health facilitator also liaised with her carers to ensure that they understood what procedure she had undergone, what medication she needed, what signs and symptoms to observe for and who to contact if needed. Some of the participants, including Catherine, also talked about going to days with the health facilitator to meet up with other service users and talk about "What's good, what's bad", where they learned about healthy living and also discussed various health experiences, such as mammograms. The health facilitator, according to participants, assists service users, their health professionals and carers in health promotion, health checks, and acute

and follow-up care. Indeed, in a service evaluation study, according to one services commissioner, “The person who got the attention of the GP was the learning disability nurse” (Gates, 2011a, p. 15). Several of the participants had known their health facilitator over many years, and the facilitator had built a good network with social and health professionals so, while the role can be effective, it cannot be assumed that these findings would be replicated in other situations. Nonetheless, the evidence from these participants supports the recommendation of the *Healthcare for All* report that primary care trusts should commission:

“... liaison staff who work with primary care services to improve the overall quality of health care for people with learning disabilities across the spectrum of care. “

(Michael & Richardson, 2008, p. 10)

Caan, Lutchmiah, Thomson, and Toocaram (2005) carried out an early focus group study (based on the work diaries of the health facilitator) of primary care and learning disability care managers into the effectiveness of the new health facilitator role. They found that it improved liaison between service users and agencies, increased engagement with health services and promoted knowledge of learning disabilities across service providers. Interestingly, a health background with experience in working with people with learning disabilities (characteristics of the lead health facilitator in the study) were found necessary to fulfil the requirements of the role, but learning disabilities nurse qualification was not seen as essential (Caan et al., 2005). A mixed-methods study, where the qualitative approach used case record analysis, interviews and focus groups with service users, carers and health facilitators, and shadowing and review of health action planning with members of the community learning disability team, was carried out in Leeds (Julian, 2008). A large number of learning disability nurses were already employed and took on the health facilitator role. However, they found limited success at the strategic level, working with GP practices to use the health action planning toolkit. GP practices defended their lack of engagement on the basis that the Department of Health collected data on waiting times for operations and access to primary care for the general population, rather than on health action planning (Julian, 2008). This study also identified that health facilitation was effective where “a relationship of trust existed between the health facilitator (or person promoting the plan) and the individual and family carer” (Julian, 2008, p. 37), echoing the findings of



the current study (see *Trusting relationships and emotional security with the health professional in the consultation experience*).

In Nottinghamshire, a descriptive discussion of the learning disability nurse health facilitators suggests progress: the number of health checks carried out, the introduction of a traffic light system in the acute hospitals to ensure reasonable adjustments are made for people with learning disabilities, and liaison with other services, such as dental care, have all improved access to care (Harrison & Williamson, 2010). Some Trusts employ separate acute liaison nurses, to support hospitals in identifying and making reasonable adjustments that need to be made for people with learning disabilities requiring acute admissions, while also supporting the service user and their family with information, consent and communication of need (Pointu, Young, & Walsh, 2009). The need for a qualified liaison nurse with an understanding of learning disability was also identified in an interview study of 12 service users and their carers (Ali et al., 2013) where issues related to needing more knowledge of medical language and understanding of how to gain access to appropriate resources were identified as significant barriers to satisfactory healthcare. Another study, looking at the hospital experiences of people with learning disabilities ( $n=11$ ), found similar communication barriers and care deficits, with hospital staff seeming to identify need in terms of their own workload, rather than the service user's need. They also found that explanations for service users were inadequate, and that they felt unable to ask questions (Gibbs, Brown, & Muir, 2008).

Various articles provide anecdotal evidence to support the value of the acute liaison nurse in improving access to acute health services, both in terms of procedural and attitudinal change (Hancock, Rubio-Mayer, & Badiali, 2011; Pearce, 2010; Trueland, 2010), but formal evaluation of this role is limited. One such study in the south of England combined a case note assessment of referrals with a thematic analysis of semi-structured interviews with a variety of service users, carers and hospital staff ( $n=36$ ) (Castles, Bailey, Gates, & Sooben, 2012). Service users in this study found hospital staff friendly, but also identified shortcomings in explanations, information-sharing and communication. However, they felt that the liaison nurse listened to them and understood them, as did the carers who found the liaison nurse's help in translating their concerns into medical language relieved their stress. Ward staff expressed a lack of experience and need for training in caring for people with learning disabilities, despite its availability within the Trust. They found liaison nurses were helpful in discharge planning, and could support them in their care and liaise with other health professionals, but thought they should be more available,

since cover was patchy due to part-time roles. The study concluded that, as well as raising awareness of the role and seeking to increase cover, the education of ward staff regarding how to implement care for people with learning disabilities should be reviewed (Castles et al., 2012). A similar mixed-methods study in south-east Scotland (Brown et al., 2012) interviewed 41 stakeholders. An interesting finding from the audit aspect of the study was that information-sharing relating to care needs was the activity carried out with the highest number (67%) of service users, while capacity and consent issues (41%) and discharge planning (40%) were the other two largest activities. Stakeholders viewed the acute liaison nurse's role in co-ordinating care, for example with pre-admission and discharge planning processes, as very important. Ward staff felt supported by the liaison nurses with communication and knowing how to meet service users' needs, while carers felt supported by someone who could help them represent the needs of the person in their care. A key role for the liaison nurses was in helping to draft responses and policies related to people with learning disabilities, which although it was potentially useful, was a concern as it might take them away from direct care. The liaison nurses were also able to facilitate reasonable adjustments, prevent poor outcomes, improve the service user experience and promote adherence to the requirements of the Mental Capacity Act (Brown et al., 2012; UK Government, 2005).

However, the views of the service users and carers suggest that many care issues are related to inadequate communication, with a fear that asking to have their concerns addressed could lead to confrontation and poor care for their relative (Castles et al., 2012). This highlights the difficulty of people acting as advocates for their sick relative and raises the question of whether information-sharing in hospitals needs evaluating, both for people with learning disabilities and for the general population. This was also identified as an issue in *Six Lives: Progress Report on Healthcare for People with Learning Disabilities* (Department of Health, 2013a), but although complaints advocacy services have now been devolved to local authorities, the cause of communication concerns in healthcare has not been fully explored. The acute liaison nurse role has general support, but they are not available for most service users, and development of the learning disability nurse workforce is needed in order to make it possible for health facilitation and acute liaison roles to be carried out by learning disability nurses. Service users and their carers believed that learning disability nurses were more able to meet their communication and health liaison/facilitation needs (Department of Health, 2013a), a view supported by the Chief Nursing Officers of the United Kingdom (Department of Health, Department of Health Social Services and Public

Safety (Northern Ireland), Welsh Government, The Scottish Government, 2013). The main health facilitator who supported several of the participants in the current study was qualified as both an adult and learning disabilities nurse, and was well-known to the service users over many years, as well as being familiar with a wide variety of health and social care workers. He acted both strategically and with individual service users, their families and formal care services, and carried out the acute liaison nurse role within the role of health facilitator.

The current study shows that, whereas a strategic role for the health facilitator is essential in developing the capability of health professionals to meet the health consultation needs of people with learning disabilities, particularly in view of previous negative experience, multiple service providers and the complexity of triadic consultations, they also need to have a more direct role. While access to mainstream services is the ideal, and reasonable adjustments should be made, some service users and their carers will need more direct support to negotiate and understand the complexities of the services they require, and to develop relationships with health professionals, while health professionals need to develop an understanding of their needs from a source they respect (Gates, 2011a). Thus, while a parallel service for people with learning disabilities is not acceptable in terms of the demand for equity and diversity, it is essential that they have access to direct support from health facilitators where required, in order to address the difficulties in communicating with, developing relationships with and understanding the language of multiple service providers, particularly where they require support from another person, and this could reduce their engagement with the consultation process. While health facilitators may help to overcome communication barriers, participants identified several aspects of the consultation that hindered communication and impaired their consultation experience (see chapter five *Communication barriers* below).

### **Conclusion – Effects of Multiple Relationships and Providers on Communication within the Consultation**

In the previous chapter, it was found that the participants identified meeting new health professionals, being in new situations, and having tests and investigations all caused anxiety and made communication with health professionals problematic. However, they are also more likely to have a number of professionals involved in their health and social care interactions. This can create stress and anxiety for them, and use the resources (time, travel costs, emotional labour, and informational support) of the person supporting them. People

with learning disabilities often need to be accompanied to health consultations for a variety of reasons: to support with transport and physical access; to help them to understand and engage with their own healthcare; to reduce their anxiety and provide emotional support; to provide key information to the health professional; to promote their personhood within the encounter; to advocate on their behalf; to liaise between different services; to aid communication; to provide support in adapting their lifestyle in response to health advice; and to keep a record of important health information for the health professional and for the person. This triadic interaction is not always managed well in the consultation, either putting too much stress on the service user to answer questions, or making them feel undervalued through ignoring them in the consultation. This has important implications for health professional education and training to promote good communication and the development of trusting relationships within a complex situation, and to allow the development of strategies to allow discussion of sensitive topics. Sometimes, even with support from family, additional help is needed to negotiate and liaise between multiple service providers, but this is even more important when support is normally provided by paid carers, particularly if they do not know the service user well. This assistance can be given by a health facilitator and/or an acute liaison nurse, but these services are not available to all people with learning disabilities, leading to inequity in access to healthcare. The number of specialist learning disability nurses has diminished, so there is an education and service development need in order to address this health gap. The key findings within this theme are outlined in table 12 below:

<b>Table 12: Summary of findings on the role of the other in health consultation experiences</b>	
<i>Finding</i>	<i>Where Evidence Discussed/Derived</i>
Multiple service users can lead to discontinuity of care, inability to establish relationships with health professionals and increased anxiety, requiring support in health consultations.	Lindsey's experience with different GPs, which led to a lack of trust/confidence in her health management; Matt's anxiety about having his accommodation needs reassessed made him reluctant to pursue his knee problems further with his doctor, so his father paid for private physiotherapy ( <i>Multiple service providers and multi-professional working/communication</i> ). Also see <i>Trusting relationships and emotional security with the health professional in the consultation experience</i> .

**Table 12: Summary of findings on the role of the other in health consultation experiences**

<i>Finding</i>	<i>Where Evidence Discussed/Derived</i>
Most participants attend health consultations with a companion (formal or informal). Informal support (usually a relative) is generally welcomed by the participants who have it.	<i>Informal support</i> - James' reliance on his mother to express his needs because he sometimes cannot remember what he wants to say, although he discusses it with her beforehand; Edmund's need to discuss his health issues with his father; Matt's support from his father – discussing his situation with him and going to a private physiotherapist.
The relative will try to develop a relationship with the health professional in order to promote the best interests of the service user – the service user's trust in the health professional is affected by the relative's relationship with the health professional, and <i>vice versa</i> . This can affect the ability of the service user to express agendas, partly because the relative is presenting the "best" self of the service user for health professional approval/liking, but some service users would like more say.	<i>Informal support</i> - James' mother talking in the medical language in order to engage the health professional's support – so James was partially excluded from the consultation; Mark's mother not asking about his headaches; Elaine not being able to express her needs and preferring to see the doctor with someone who was not her mother. <i>Formal support</i> - relatives less likely to take service users to the doctor than paid carers (Turk et al., 2012; Perry et al., 2013). Sensitivity to how the relative and service user are each treated is shown by Lindsey and by Elaine's mother, and they are aware of being liked or not liked – <i>Individual personality/relationship with health professional</i> ; (Alborz, McNally, & Glendinning, 2005).
Despite wishes to express some concerns more, and possible difficulty in talking about sensitive topics, such as sexual relationships, in front of relatives, service users welcome their support, and a key role of the relative is that of representing the personhood of the service user in the consultation.	(See James and Elaine above and in <i>Informal support</i> and <i>Formal support</i> and Laidsaar-Powell et al. (2013) for difficulties in discussing intimate/sexual issues). Roles of the companion outlined by Cordella (2011) and importance of personhood shown <i>inter alia</i> by Rolf's mother and Elaine's mother encouraging the doctor to talk to them in <i>Involvement in communication/ inclusion</i> ; supported by literature on triadic consultations (Cahill & Papageorgiou, 2007) that health professional behaviour towards service user can influence communication.

**Table 12: Summary of findings on the role of the other in health consultation experiences**

<i>Finding</i>	<i>Where Evidence Discussed/Derived</i>
Relatives are generally highly regarded and given more status within consultations than paid carers, partly because they have more detailed knowledge of the needs/medical history/health surveillance of the service user, but health facilitators can fulfil a similar role if they know the person well. Paid carers do not always have the knowledge or information to fulfil this role.	Ann's carers did not keep records of her seizures, and she was accompanied by several different carers to her health consultations – <i>Formal support</i> ; paid carers seen to be less able to assist health professionals than learning disability nurses or relatives (Gates, 2011a; Michell, 2012); Catherine's carers did not help her to modify her lifestyle in response to advice, and needed to attend consultations with her ( <i>Formal support; Explanations and understanding in consultations</i> ).
Health facilitator role effective in supporting service users' access to mainstream health services, including psychiatric service; in this geographical area, health facilitator also undertook acute health liaison role, but this service could be more available.	Edmund's experience of managing his diabetes, managing his needle phobia and accessing psychiatric support ( <i>Health facilitator role</i> ); Jonathan's experience in being able to make an informed choice not to consent to surgery, and accessing psychiatric support during bereavement and understanding his medication ( <i>Listening</i> ); Catherine's involvement in health promotion, help with discharge planning and communication between health professionals and carers ( <i>Formal support; Health facilitator role</i> ); supported by evaluation studies of acute nurse liaison role (Brown et al., 2012; Castles et al., 2012).

A model of how the triadic relationship, multiple service providers and the health facilitator/acute liaison nurse role affect the experience of the health consultation can be found in Figure 6: Model of possible effects of the triadic consultation, with/without health facilitator support (see *Relation to literature on triadic health consultations*).



## ***Chapter 5: Communication Barriers: Anxiety, Embarrassment and Stigma***

### **Introduction**

It has already been noted that some participants felt they were not listened to or recognised in health consultations (Rolf, James) while Rachel, Henry and Lindsey felt a dislike of some or all doctors. Ann had not expressed her fears about her worsening epilepsy, while Matt felt his knee problems had not been properly managed because he had learning disabilities and was therefore not valued by the doctor. Daniel, Elaine and Penny all experienced feeling too shy to talk in consultations or talk about their concerns, while Jonathan and Rolf had been excluded from their own consultations by the health professional only communicating with their carer. Lisbet preferred not to take an active part in her health consultations. A combination of anxiety, lack of involvement in health consultations and decisions by his mother about which agendas to discuss in the health consultation mean that Mark has been unable to discuss his fears that he may have *"something on the brain"* with his doctor or nurse. However, participants also identified other confounding factors that caused barriers to their communication within the consultation and reduced its effectiveness. These categories were grouped together to form the theme Communication barriers: Anxiety, embarrassment, shyness (See Figure 3 below).



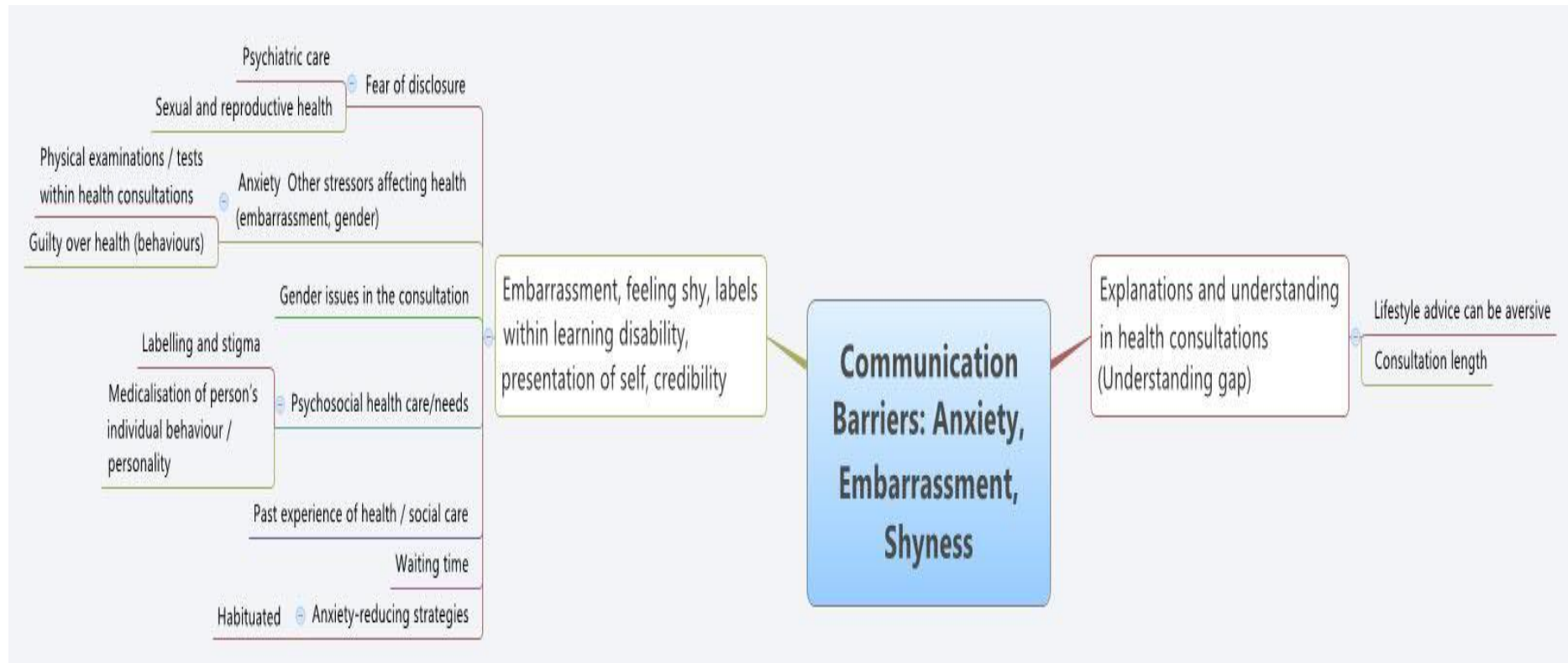


Figure 3: Communication barriers: Anxiety, embarrassment, shyness: thematic representation

## Explanations and Understanding in Health Consultations

The main purpose of annual health checks is to identify any health needs, investigate them and refer the service user to specialist services where appropriate. When service users attend for health checks and other consultations, they are likely to undergo tests and investigations, but several participants identified that they would like more explanation of the findings from them. For instance, Daniel, who does not speak in his health checks but has undergone related medical tests:

*H: Can you give me one thing you would like to have said?*  
*Daniel: Ermm, how's my, how's my head; and, ermm, ermm, ermm, how's, how's, how's my, how's my chest: how's my heart...*

It is clear from this that Daniel's fears related to the outcomes of those tests have not been addressed in a way that he has understood, causing him anxiety. Similarly, in James' consultation, the health professional identified that there was protein in his urine as expected, but did not respond to James' cue of wondering what that meant (see *Cues and prompts in consultations*), leaving him to conclude that it was a "nuisance". When asked about reproductive and sexual health advice, Rachel and Grace gained most of their information either from informal conversations or from what they had learned in school, but added that leaflets were available:

*Grace: The leaflets are in the doctor's, you can get them yourself, they're in ermm... Well at our doctor's, they're in...they've got like, ermm, like a thing on the wall, and they're all in, all these different leaflets...Sometimes they might say which one to get... Sometimes they get them for you,*  
*Rachel: ... I suppose if you weren't sure, you could tell them, couldn't you, and they'd get you the right ones...*

This suggests that their understanding of the different options related to contraception and sexual health may not have been managed as closely as the contraception itself, and that more active attempts to use leaflets and other resources as part of explanations have not been made for these participants.

Lisbet is distressed that her mobility has deteriorated to the point where she is completely reliant on her motorised wheelchair but does not understand why:

*Lisbet: Not me, not walk [...] Two legs.*  
*H: Both legs. Right. Do you know why?*  
*Lisbet: No.*  
*H: Has the doctor explained it to you, or the nurse? Did they try to tell you why...*

*what's happening, what's wrong with your legs?*  
**Lisbet:** *Don't know.*

Despite Lisbet's concern about her loss of mobility, she does not understand what is causing it and does not know if it has been explained to her. clarified in the member check, when it transpired that Lisbet had been advised not to walk immediately after an operation, and did not realise that this was only a temporary instruction (see Appendix 10 *Member check*). The nature of having learning disabilities means that the service user may have more difficulty in understanding an explanation or being able to evaluate or question it, as well as being able to retain the information afterwards. Even then, they may not be able to recount the explanation to an interviewer. In the context of the focus group, Lisbet introduced this subject without being questioned about it, indicating that it was a matter of pressing concern, showing a need for explanation and information support. This suggests that she does not feel completely satisfied with her health consultation experiences. Lindsey identified that she would ask the nurse if she wanted an explanation of her healthcare, but is unlikely to ask a doctor, which relates to previous experiences of medical consultations and her father's mistrust of doctors, combined with her "shyness" and difficulty in hearing and understanding everything that is said, especially in medical language:

**Lindsey:** *... Some of the doctors I don't understand what they're saying [...] That's why I need someone with me... To understand what they say [...] and another person to explain it all to me.*

This is compounded for Grace by the difficulty of understanding a doctor with a foreign accent:

**Grace:** *Well, he went, and then some foreign chap - I couldn't understand anything what he were saying, so I went to the nurse after that - at least I can understand what she's saying to me.... Sometimes it's too quick isn't it what they're telling you....*

The attribution that Grace gives to the doctor's accent being a cause of communication difficulty is impossible to assess, but it is her view, although it possibly reflects the views of other people in her life. The geographical area covered in this study may not be as ethnically diverse as some other areas such as Leeds and London, where service users and their carers who are labelled as black minority ethnic have found it difficult to understand and communicate with doctors and nurses (Ali et al., 2013; Julian, 2008). Nonetheless, any barriers to understanding will compound the cognitive barriers

experienced by people with learning disabilities. James is also aware of his own difficulties in understanding the consultation and being able to contribute: *"It's like it's filled with petrol and suddenly when you're thinking, talking, you just forget"*. Lindsey tried to explain her recent ill health, which manifested as extreme fatigue:

*Lindsey: [...] The thing is very low... I get.... I can't say it... I get... Ooh, I can't think... Oh God... It's something else... Very very low... Something very low...*

*H: ... In your blood? Or... How do they test it?*

*Lindsey: I had a camera down my throat [...] I went to (oncology centre) [...] to have it done [...] And all the rest is... And I'd be all right... And the doctor said... He got me weighed... To see what the weight is... He says I'm doing okay... And then the other days, they think I've put on weight.*

However, she struggled to remember the medical words that had been used and did not really understand what was wrong with her, or why she had undergone tests, only that the outcome was that she would be alright. One indicator that she was not deteriorating was that her weight was recovering, so now she is confused because her weight gain is seen as unhealthy and she has been put on a reducing diet. Similarly, Mark was able to remember having his blood pressure taken, but also said he had a routine X-ray, but did not know why, and when asked what his blood was tested for, said:

*Mark: ...To check to see whether you require more treatment or something. Some things require more than treatment.*

Catherine had a discussion, with one of her carers and the health facilitator, about the importance of having a carer with her when she went to see the nurse or doctor. Although she had previously been happy to attend health checks unaccompanied, information about her dietary and lifestyle needs had not been communicated to her carers. Catherine appears quite self-confident and verbally fluent, but even though she seemed to understand things in the interview, she was often not able to explain or remember them when asked. When she had been seriously ill, Catherine had told her carers that she felt alright, but they observed that she was not well and called in the doctor, resulting in Catherine having major surgery. This difference between outward social skills and actual cognitive skills and self-awareness can lead to over-estimation of understanding, with potentially dangerous consequences. This makes it difficult for health professionals to rely on the service user's information, especially if they do not know them well enough to judge their ability to contribute information, understand explanations and communicate with carers. This underlines the role of the companion as health advisor as discussed in *Role*

*of the other in health consultations* and provides additional support for the importance of the health professional knowing the service user well.

Ann was interviewed with support from her day centre carer. She was keen to discuss a particular examination or test that she had experienced, but despite several minutes of trying to work out what she was trying to tell us about, we were unable to understand her. Ann was aware of this as a problem in her health consultations:

*Ann: Do you know... Do you know what I'm saying?*

*Carer: I do now, yeah*

*Ann: Well she doesn't know what I'm saying, at (the medical centre)*

*Carer: Oh okay, that's why CT and carer E both go with you then*

This illustrates some of the barriers to communication in the health consultation. It is difficult to know what the person has understood and what they are able to remember, and they may say “yes” to please the health professional or to relieve the stress of being asked questions that they cannot answer. They may also be unable to communicate their concerns or ask questions, simply because they do not have the language skills to do so. Additionally, consent to any examination, test or treatment could be assumed, when it is compliance without being fully informed. Verbal explanation of examinations or procedures may be insufficient, and physical demonstration in order to gain consent was found preferable by people with learning disabilities in the Netherlands (Wullink et al., 2009). One or two participants were aware of resources that are available to the general public, such as leaflets and information via the internet including specialist “easy-read” websites and downloadable literature. However, the majority of participants did not identify the use of information leaflets or websites to support explanations. The accounts of these service users suggest that they are generally compliant with their healthcare professionals, but do not always understand what is being done to them and, particularly, why it is being done. It can be seen as promoting autonomy to facilitate service users to attend for health consultations unaccompanied, but it can result in ineffective communication, reducing the value of the health consultation and potentially having a negative effect on health outcomes.

In their questionnaire study of 126 family doctors and patient dyads (630 patients) Hagihara and Tarumi (2006) looked at patient understanding of explanations within the consultation and perceptions of health outcomes, asking both the doctor and the patient whether they thought the doctor’s explanations of tests and of treatment was sufficient. They theorised that the patient would evaluate the doctor’s explanation as insufficient if

they could not understand it, but as sufficient if they could, while a doctor would judge it as insufficient if they did not think the patient understood it, and *vice versa*. Therefore, they hypothesised that if doctor and patient made the same judgement, they would be concordant and patient outcome measures (see Table 13: *Patient outcome variables*) would be better.

**Table 13: Patient outcome variables measured by Hagihara and Tarumi (2006)**

• Understanding of doctor explanation (medical testing)
• Understanding of doctor explanation (treatment)
• Improvement of health and fear
• Satisfaction with care
• Impression of doctor (friendliness)
• Impression of doctor (courteousness)
• Impression of doctor (impatience)
• Poor compliance (self-regulation)
• Poor compliance (ignorance)

However, the best patient outcome was actually found to be when the patient rated the doctor's explanation as being more substantial than the doctor did, while a more positive assessment of the explanation by the doctor than by the patient was associated with poorer patient outcomes. A more experienced doctor and a male patient were both significantly less likely to produce a doctor-better evaluation of medical testing and treatment explanations, while a lifestyle change explanation was significantly more likely to produce a doctor-better evaluation. In addition, knowing the doctor for longer was significantly less likely to produce a doctor-better evaluation. Given the findings of the current study that several participants had difficulty in understanding explanations by health professionals, this suggests that they are likely to experience poorer consultation outcomes than if they felt they understood their health professional. In an interview study of 14 patient-carer dyads and one carer (carried out in London), into barriers to accessing mainstream healthcare, over half the participants had experienced discrimination against people with learning disabilities (Ali et al., 2013). There were difficulties in communication and attitudes towards service users, and participants felt they were given inadequate information about "diagnosis, procedures and medication regimes" (Ali et al., 2013, p. 5). The issues around communication were similar to those found in the current study: service users not being listened to; difficulty in expressing agendas; and inadequate explanations and consent procedures (Ali et al., 2013).

Jonathan had a better experience with his practice nurse who used special easy-read leaflets that she downloaded from the internet, to help with her explanation. She also wrote things down to help him understand and remember key points. Similarly, Edmund has found that the combined explanations of the health facilitator and the practice nurse had helped him to gain control of his blood glucose levels related to his Type I diabetes. Edmund and Jonathan both felt motivated and validated by the explanations of their health needs because their viewpoints were considered and the relevant physiology explained in a way they could understand and use. They had felt disempowered by previous health consultations, but felt empowered by his recent encounters with the practice nurse, supported by the health facilitator. This suggests that the need for acceptance of the patient's perspective, tangible explanations, plus support to self-manage, without blame (Salmon, Peters and Stanley, 1999) applies to all patients, not only those labelled as having somatising disorders (persistently seeking medical help for physical symptoms with no apparent physiological cause).

Several of the participants perceived their own limitations in understanding health consultations, and this cognitive barrier to communication can lead to a sense of helplessness and disempowerment. It has been identified that people with "low intellectual ability, which is typically found to be positively correlated with poor verbal recall and high suggestibility and acquiescence" (Gudjonsson & Clare, 1995, p. 333) are also more likely to confabulate. Confabulation is where people who have difficulty in processing information unknowingly replace memory gaps with imagined information or events that they believe to be true (Gudjonsson & Clare, 1995). This combination of wanting to please others (often by saying yes to yes or no questions), having difficulty in remembering information, responding suggestibly to questions and being prone to confabulation means that health professionals need to take care in how they ask questions and in cross-checking information without confusing or appearing to interrogate the person. In particular, checking understanding by asking someone if they understand is likely to lead to a false positive response. In the current study, where health professionals made attempts to explain their health needs in a way that participants could understand, sometimes by using easy-read leaflets or by writing down the key points of their explanations, and with additional explanation by the health facilitator, this gave participants a sense of control over their health and satisfaction with the consultation.

The current study shows that clear explanations at a level that the person can understand give them a sense of control and satisfaction with their consultation, yet

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trainee GPs tend to under-perform in the person-centred communication aspect of their video-taped skills module assessment, incorporating the skills of exploring the patient's explanation of the illness, giving an explanation related to those beliefs and checking the patient's understanding of that explanation (Campion, Foulkes, Neighbour & Tate, 2002). Nurses are expected to use person-centred communication to care for patients and to promote self-management of long-term conditions and, while nursing is primarily seen as meeting people's care needs, a key aspect of this involves meeting psychological needs and explaining care (Nursing and Midwifery Council [NMC], 2010). Although communication skills are an essential aspect of practice placement assessment, there is no specific assessment of explanation-giving within pre-registration nurse education. Practice nurses, although requiring specific training for certain aspects of their role, such as cervical screening and immunisation, may not have training in managing health consultations (Royal College of General Practitioners [RCGP], 2012). Advanced Nurse Practitioners are qualified to autonomously assess patient's health needs, request examinations, make a differential diagnosis, advise on self-management and prescribe some medication (NMC, 2012) and their skills assessment involves a mock consultation. However, there is little literature on explanation-giving in consultations, and even less related to nurse explanation-giving, possibly because the Advanced Nurse Practitioner role was only formalised in the early 21<sup>st</sup> century (NMC, 2012). Nonetheless, participants in the current study did identify some positive health consultation experiences, particularly with practice nurses and health facilitators.

A conversation analysis of 100 consultations where primary care patients with diabetes and in a cancer outpatient clinic were seen by both nurses and doctors found some qualitative differences in the style of explanation between doctors and nurses (Collins, 2005). Doctors tended to have a pre-conceived structure for the consultation, generally focused on medical explanations and interventions, so patients sometimes missed the opportunity to ask questions or seek clearer explanation. Patients found nurses more approachable, were more likely to suggest their own explanations to the nurse, and to seek clarification of the doctor's explanation, a finding congruent with the current study, where Lindsey and Grace found it easier to understand the nurse and ask questions. In the study by Collins (2005), nurses were likely to focus on behaviour change, but were less likely to give the medical rationale for why the changes were needed, to the detriment of the patient's understanding. Sometimes, nurses and doctors gave different interpretations of test results, and they did not inform each other of patient communications, leading to



patient confusion. The more advanced, autonomous nurses seemed to combine the medical and patient agendas more effectively by exploring the patient's lifestyle, then the medical assessment and clinical and lifestyle changes, but there was no difference in consultation length (Collins, 2005). These findings were echoed in an interview study of patients' views of their diabetes nurse consultations (Stenner, Courtenay, & Carey, 2011), where key advantages were identified over GP consultations. These included more flexibility of consultation time, greater emphasis on explanation, tailoring information, advice and treatment to their needs, managing a number of interconnected problems in the same consultation, and continuity of relationship. In addition, nurses could make medication adjustments over the telephone, while patients had to make an appointment to see their doctor for the same service. These findings support the earlier findings of the current study (*Emotional security with the healthcare professional*) that continuity of care (knowing and being known by the health professional) is an essential component of emotional security, and therefore effective communication, in the consultation. It suggests that the diabetes nurse prescribers, because they are more available and there are fewer of them in one practice, are more likely to provide continuity of care than a GP. One mechanism by which this improves care is put forward by a patient, who identifies that different health professionals explain things differently, so it is confusing trying to connect them together, whereas it is easier to share one conceptual view with the same person (Stenner et al., 2011).

A similar situation is often found in GP practices that offer the DES for people with learning disabilities, where one nurse manages a caseload of patients who are recorded as having learning disabilities, and gains specialist knowledge of both the individual service users and their families, and of various aspects of learning disability needs and care, often supported by the specialist healthcare facilitator. An inclusive study (Michell, 2012) in which service users collected data by visiting different GP practices to find out about the DES health checks that they offered to people with learning disabilities not only evaluated what they were told about the health check services, such as how long appointments were for, whether home visits were offered, the use of "easy-read" literature and what the doctors thought about the health check, they also related how they were treated by the GP practices they visited; and there was an evaluation by one of the researchers of his own health check. If they were kept waiting, if the doctors were not interested in the research, they were able to relate that to the standard of health check provision. This study outlined the reasonable adjustments necessary to make health checks worthwhile for the service

user, and emphasised the importance of thorough physical assessment and giving clear explanation to the person, but one service user remarked on the fact that he had known his doctor for ten years, supporting the importance of being known as a factor in effective communication.

In their meta-analysis of research comparing nurse practitioner consultations with medical consultations, Horrocks, Anderson and Salisbury (2002) found that patients were generally more satisfied with nurse practitioner consultations but there was no difference in health outcomes. Nurse practitioners generally carried out more investigations and their consultations lasted longer, with one study also showing they gave more explanation. This supports findings in the current study that participants generally find explanation helpful in the consultation, even if they need further explanation by the health facilitator or their companion in the consultation, and nurses have been specifically identified as providing this by two of the participants. From 40 videotaped nurse prescriber consultations and 165 patient questionnaires for patients with dermatological conditions, followed-up with interviews with the nurses, Courtenay, Carey, and Stenner (2009) found that 93% of patients found the nurse's explanation of their problem or treatment to be very good or excellent, with similarly high scores for listening, caring and making them feel at ease. These findings were supported by the video-recordings and highlighted by the nurses' emphasis on the importance of developing a relationship with the patient in order to prescribe effectively. This supports the findings in the current study where participants have found the practice nurse (generally an Advanced Nurse Practitioner) helpful in providing explanation to support their treatment decisions and disease management, particularly where there is good communication with other health professionals, often supported by the health facilitator. The role that practice nurses play in lifestyle advice (Collins, 2005) was also found in the current study and is discussed below (*Lifestyle advice can be aversive*).

### ***Lifestyle Advice Can be Aversive***

Edmund said that he found the lifestyle advice given by his practice nurse to control his blood sugars helpful because "*understanding what the danger of diabetes is [...] and understanding why they need to do it I think helps.*" He still finds it difficult to eat healthily and exercise regularly, but by thinking about the advice he has been given, combined with the nurse "*telling me things like if I don't look after myself I could be dying*", he has started to lose weight and reduce his previously very high blood glucose levels. However, Edmund

was also influenced by an acute health crisis that he could directly relate to the effect of alcohol causing a diabetic coma:

*Edmund: I can't remember. I was off my face. I was literally very drunk. I just remember... remember someone saying I had these big posts under me backside to help flood...get all the alcohol out and I couldn't sit down for nearly about a week. It was horrible and I felt so ill. [...] But now [...] I know my limit, when to stop*

His response to this warning contrasts starkly with Rachel's response (see *Formal support*) to a similar statement by her practice nurse:

*Rachel: The nurse... She said it might be... It was that high, or summat... And she turned round and said, you might have heart-attack. So, of course, she shouldn't have said that, because I was worried, about my stomach and everything, and... I was that frightened [...] I was crying...*

These examples of different responses to a similar message clearly identify the difficulty in using one explanation and rationale to motivate people to modify their lifestyles, especially in balancing different levels of risk. In particular, the information that, unless lifestyle changes are made, the health problem could lead to death, is a particularly blunt tool with potentially harmful consequences to the person's emotional state and relationship with the health professional. Increasing anxiety where the service user does not feel able to make changes, or does not understand the relative level of risk, could in itself increase the danger to health. Differences in understanding, anxiety, self-efficacy and levels of trust in the health professional, as well as the way in which the message is communicated, can all affect how people respond to health explanations. This emphasises the importance of knowing the service user well and ascertaining their understanding of health before giving advice that they can understand and will find motivating.

In an interview study of 21 patients of Pakistani origin with type I diabetes, Bissell, May, and Noyce (2004) explored their experiences of living with diabetes and, more specifically, their relationships with health professionals. Nearly all of the participants knew the dietary and exercise changes they needed to make, though all but three had found difficulties with making those changes. Barriers to lifestyle change included financial issues, fitting dietary requirements into family meals, wanting to eat foods that they knew were unsuitable because they liked them, fitting appropriate meals into the working day, and difficult life events, such as the death of a parent. Although the expert advice of health professionals was valued, participants sometimes felt doctors did not understand their life

perspective, that they were not given time to explain it, and that they were blamed when their blood sugar control was poor (Bissell et al., 2004). In the current study, when Henry was swimming abroad in the Special Olympics, he had to be admitted to ITU with peritonitis, which his landlady explained was due to over-indulgence in fatty foods; he stated that he had "*learned his lesson*" now, showing that the concept of blame for ill health could be seen as a cultural norm, influenced by medical discourse. Indeed the NHS constitution urges people to recognise their responsibility for their own health and that of their family (Department of Health, 2013b). Increased evidence of the cost of unhealthy lifestyle behaviours to the individual, their family and the state, and discussion of the duty of government to promote public health through lifestyle change, have sharpened the focus on public health in the education and practice of health professionals (Jochelson, 2005) so that every consultation is a lifestyle advice opportunity (Bailey et al., 2012).

Some of the participants in the current study found lifestyle advice unpleasant or aversive:

Owen:        *When I went to the doctors, the last time [...] To see me own Dr, Dr (name) [...]he told me off. I don't know why. [...] He said... I put... Was putting too weight... Too much weight on the rear [...] and he told me to get it down.*

This feeling of being "*told off*" is not only unpleasant, disempowering and damaging to the relationship between the person and the health professional, but it can also lead to reduced self-esteem for the individual, as we saw with Rachel in *Informal support*, when she disliked the look of herself in the mirror after the nurse had told her she needed to lose weight. As a consequence, Rachel has refused to see that particular practice nurse again, and is anxious about future consultations. Even the doctor she likes could sometimes be off-putting:

Rachel:       *She's, she's given me eardrops, because I've told her about this cough and she said "have you been smoking". I said "no". "Do you smoke?". I said "no".*

Tony was also upset and saw himself as overweight when he was advised to lose weight:

Tony:        *Yeah (laughs) "lose a bit of weight" [...]*  
H:            *How did you feel about that?*  
Tony:        *I am gutted!*  
H:            *do you think you're overweight?*  
Tony:        *Yeah [...]*  
H:            *So did... What did the nurse tell you to do about it*  
Tony:        *Lose a bit of weight... Bit more exercise [...] go swimming [...]A bit more*

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*apples... A lot more apples*

However, he did have some strategies that he could control in order to lose weight. In addition to the potential negative effects of lifestyle advice even when the person can control their health behaviours, this is compounded if there is a communication barrier between the health professional and people or organisations with control over the person's lifestyle. The social needs of service users and the prescribed healthy lifestyle are not always congruent, so that social carers may prioritise emotional well-being and inclusivity over physical well-being, giving rise to possible feelings of helplessness and self-blame when confronted with the biomedical values of the healthcare professional. At the same time that Owen told me his doctor had advised him to lose weight, he also said that day services had given him a wheelchair so that he could join in with a group of service users going to the café in town. This situation where the health professional advises the service user, who does not always have full control over their lifestyle, was expressed by a few participants. For instance, Catherine was advised by the practice nurse that she needed to increase her exercise, particularly walking, so that she did not lose the ability to walk. She was happy that she was being active, describing the activities she carried out in the day centre, including playing dominoes, reading for pleasure, noughts and crosses, as she had been moved from the "top end" activities, such as dancing, down to the "bottom end". Catherine did not perceive that this was at odds with advice to keep active, and the change had been made by staff in the day centre to accommodate Catherine's functional abilities and social needs.

There may be other reasons why health advice cannot be carried out by the person in an institutional setting. The advice given by the practice nurse to Jonathan that he needed to exercise regularly was not always practical, because the carers could not always go out with him due to a fellow resident being unwell and his exercise bicycle being broken. However, since the advice is documented and filed in his care records, it provides guidance (even a requirement) for the care organisation to support this aspect of his care. Thus, health professional lifestyle advice can have a positive effect on the life opportunities of the person if documented and communicated to the care organisation. This was reinforced by the support of the health facilitator visiting Jonathan in his home and liaising with his carers. To address this concern, Murphy (2012) suggests that health advice and support can be given in an informative and enjoyable way through discussion groups that have promoted a variety of health behaviours and enabled service users to be informed about a range of topics from health screening procedures to lifestyle advice. This is an important

aspect of being able to give informed consent for screening procedures (Truesdale-Kennedy, Taggart, & McIlfatrick, 2011). The discussion groups enabled participants to set personal goals and to make supportive friendships in the process. It also promoted greater understanding of the healthcare needs of people with learning disabilities in those health professionals who took part. Referrals were made by the learning disability team, but it was unclear if outcomes were shared with GP practices. In addition, although this is a way of health services ensuring that the health information needs of those service users are met, it is clearly an additional service providing support because healthcare provision is unable to make the reasonable adjustments required for health promotion, for ensuring informed consent for screening procedures, and to correct their poor uptake (Emerson et al., 2012) in people with learning disabilities. Moreover, in a mixed-methods study of the effectiveness of group health promotion activities with people with learning disabilities ( $n=38$ ), Codling and Macdonald (2011) have found that, although the participants' knowledge of the subjects was increased (using pre- and post-test questionnaires), the focus group data indicated that this had not led to any significant lifestyle changes among the participants, although they had enjoyed the sessions. They suggested, therefore, that this approach was economically unsustainable as it did not achieve observable improvements in health behaviours and, rather than aiming public health information purely at the service users, they should support carers, relatives and relevant organisations to provide a similar service (Codling & Macdonald, 2011). The implication is that it is possible to achieve a high standard of communication, in an enjoyable way, about health with people with learning disabilities, but that the health outcomes are not achieved, so the service is unsustainable. In contrast, members of the discussion group described by Murphy (2012) were encouraged to set goals and keep diaries, as well as to take part in delivering sessions once they had gained experience. Thus, behavioural outcomes were demonstrable. Economic sustainability means demonstrating an observable health improvement from health professional input. Health checks, although communication may not always be optimum, demonstrate reasonable adjustment and may be more realistic, especially if carers or relatives are involved in the consultation (see *The role of the other in health consultation experiences*). However, not all interventions can be "brief", especially with people with learning disabilities. The importance of developing relationships in order to reduce anxiety and produce change over time is essential to promote health autonomy in people with learning disabilities, as can be seen with Edmund in *Strategies to reduce anxiety*.

Even where the service user does have a sense of control over their own lifestyle, the advice given can seem limiting, as Grace and Rachel discussed:

- Grace: They tell you all sorts... (Rachel: yeah... Yeah)... Don't drink alcohol, no coffee, no tea... No this, no this, no this, that, and the other!... You'll be living on water and ruddy bananas! [...]. They say we shouldn't be eating this...*
- Rachel: Yeah!...*
- Grace: ... And we shouldn't be eating that. We shouldn't be having this...*
- Rachel: Yeah!...*
- Grace: ... And we shouldn't be having that. We won't be able to breathe next! (Laughs)...*
- Rachel: Yeah! You shouldn't be eating cake, you shouldn't be eating chocolate... [...]*
- Grace: You can't do this, and you can't do that, and you can't do the other [...] as long as it's all in moderation, you can have it, you just don't eat it like a cake for breakfast and lunch and tea.*

Although it is important for information to be given at a level that service users can understand, simplifying advice by using a rule-based approach can leave service users feeling infantilised and helpless. Increasing stress and anxiety associated with health consultations by giving advice that the service user finds aversive is likely to reduce the effectiveness of the consultation and make it harder for the person to ask questions or express their concerns because they feel devalued within the relationship. Matt found the thought of being referred to the doctor with high blood pressure particularly stressful:

- Matt: I didn't like the way she's "Ooh, you'd better... You know, we better get the Dr", and me Dad's thinking, "I don't think... You know... had he... You know, is he?... To me he looks okay.". "Oooh well, I need you to come in." And... And me Dad says. "Well, to me he looks okay". You know, and she was one of... Particular nurse was a bit old-fashioned, and if your blood pressure was just a little bit higher than... or e...than it should be she, you know, "Oooh... Dear... Ooh", you know.. She'd make more of it than there needed to be. You know what I mean?*

Again, the nature of the relationship within the consultation affects the way the service user views the advice of the health professional, and anxiety created by past experience of doctors can increase resistance to referral by the nurse. So, whereas Matt found the possibility of referral to a doctor unpleasant, one of the common outcome measures for the success of health checks is the number of referrals for previously unidentified health problems (Robertson, Roberts, & Emerson, 2010). Thus, the goals of health professionals and of the service user, while both seeking the best outcome for the person, may not achieve it if concordance is not achieved (Bissell et al., 2004). Matt identified that he did not normally see this nurse, which may have contributed to the difficulties in communication between them.

James, who has quite complex health needs, was given advice by his nurse practitioner about fluid intake and breast self-examination and testicular self-examination. The nurse practitioner showed James, using a litre bottle of water, how much fluid he needed to drink in a day (two bottles), and when she carried out breast and testicular examinations, she showed James how to examine himself and advised him to do that in the shower. This use of concrete examples and experiential learning is a helpful approach for gaining confidence in the skill and for recall, particularly for people with learning disabilities. However, it takes time to understand the person's viewpoint, assess their needs, formulate explanations and check understanding in a consultation, particularly when communication may be slowed down to support the person with learning disabilities and to include the service user's companion. Some participants identified *Consultation length* as a barrier to effective communication.

### ***Consultation Length***

Matt had his annual health check with a female GP whom he likes and felt he had the opportunity to talk about his concerns, but thought the appointment was too short.

*Matt: .... a fifteen minute appointment, you know [...] because she's got other patients waiting outside, you know, this is the problem, you know. There's a queue of people, you know, and she has to see all these people in a space of time, you know [...] but, sometimes, it depends how many she's got in her surgery, you know. I mean she can't be all day, because, you know, she's got other patients [...] she even asked, ermm, was there anything, you know, and we said everything was fine....*

Although this suggests that Matt might like more time with his doctor, it also highlights the value he places on seeing her because he knows and trusts her, so perhaps less time is needed to set the context for the consultations. Daniel, however, who was unable to ask questions about his test results and find out if he was alright, blamed it on insufficient time for his consultation:

*Daniel: .... I'd ask, is it normal?*  
*H: Did you.... Why ..why do y-you think you didn't ask at the time? What stopped you?*  
*Daniel: No, er, lack of....lack of clock [...] no time.*  
*H: How long did you have?*  
*Daniel: Errr, ab... I had half an hour [...]*  
*H: But there wasn't enough time for you to ask if you're tests were normal?*  
*Daniel: No.*  
*H: So, if you went to see the doctor again...what could the doctor do to make it better?*  
*Daniel: Just (indistinguishable) more time, more time (indistinguishable), was time to*

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*answer the questions [...]*

*H: Do you think the doctor should have asked you if you had any questions?*

*Daniel: Yeah, but, it takes time, don't it, it takes time, to ask them.*

This supports the findings of Ogden et al. (2004) that people were more likely to feel that their consultation had lasted an insufficient length of time when they were less satisfied with the emotional content of the consultation and were less likely to adhere to medical advice. Daniel feels that there is insufficient time in the consultation for him to ask a question about whether his test results were normal, despite the consultation lasting half an hour. Consultation length has been studied as a literal cause of inadequate communication, with the consequence that appointment times have increased (Ogden et al., 2004), but the feeling of insufficient time seems to be a consequence of poor communication, rather than its cause.

However, not all participants wanted a longer consultation. Mark preferred “*to get it over and done with*” and Roddy thought that although his consultation did not last long, it was sufficient. Throughout the interview process for the current study, participants had widely differing communication styles, so that some would want to express more than others, some would find it easier to understand what I was saying than others, while some took longer to express their thoughts than others, but really tried to engage in the process, for example Ann in *Explanations and understanding in health consultations*. If the health professional tries to include the service user, but that person’s communication style takes longer to understand, this could, in the short-term at least, increase the consultation length, and may partially explain the earlier finding that service users are not always included in the consultation (see *Involvement in communication/inclusion*).

As we have seen in *The role of trusting relationships in effective communication*, the time needed for the consultation will vary with how well the health professional and service user know each other, as context and familiarity with communication style assist communication. Additionally, consultation length will vary with the expectations of the service user and the information needs of the health professional, which will be influenced by whether the person has had previous health checks. Rolf identified that the nurse asked a list of questions to his mother, who had to point out that Rolf could answer some of the questions. Annual health checks are usually based on a checklist, such as the Cardiff Health Check template, but the Royal College of General Practitioners recommend that this is used within a consultation for which service users and their carers have prepared a health action plan in advance (Hoghton, 2010). By working through the checklist with the mother and

focusing on processing information, the nurse made Rolf and his mother feel that Rolf was being excluded from the consultation. This would explain the finding of Pawlikowska et al. (2012), where relaxed hands were associated with high patient enablement, as this precludes inputting data into a computerised checklist and suggests active listening, where non-verbal and verbal behaviour focuses on the person (Robertson, 2005). Daniel also felt excluded by the number of questions his carer was asked about him:

*Daniel: ....questions, questions, questions, like err, you know, you know, when there's a shelf of them, you know when there's a shelf [....] You know, paper. [....] He'd keep going back to them [....] lots of questions, backwards and forwards*

This explains the findings of Peltenburg et al. (2004) that, while consultation length did not account for the emergence of agendas within the consultation, the percentage of that time spent listening did.

Expectations of time needed will also be influenced by the person's view of how much time they are entitled to – Matt and Daniel were both aware of the limits on the health professional's time, echoing the beliefs of the participants in Bissell et al.'s (2004) study that the doctor did not have time to listen to their personal experiences of diabetes. A perception that the health professional does not have time to listen to the person's perspective is not an objective measure of the time available, because there is no statistical relationship between the two (Peltenburg et al., 2004). However, when a patient feels that the health professional has avoided listening to their personal perspective (Robertson, 2005), it is a blame-free rationalisation. In their interview study of people with rheumatoid arthritis or a general non-inflammatory condition, such as fibromyalgia, Haugli et al. (2004) found that participants explained doctors not having time to communicate effectively with them as being physically but not mentally available, and that they could not ask questions that the doctor might see as irrelevant and therefore time-wasting. Active listening requires emotional and cognitive energy, so performance can be difficult to sustain, emphasising the importance of a long-term relationship to allow for development of a dialogue over time. Overall, the current study suggests that the listening behaviour and engagement of the health professional is more important to the service user than the length of time the consultation lasts, but that other factors may affect the time needed to express and consider the service user perspective.

The complexity of the person's health needs may affect the total amount of time that they need to address all of them. With an initial health check, this could increase the

amount of time needed to complete the information-gathering exercise, but with the risk that the service user might become fatigued and find it difficult to contribute (as with James in *Explanations and understanding*). Alternatively, health professionals might “chunk” agendas up into different consultations (Robertson, 2005), but the finance reward for the DES health checks does not provide an incentive for this and, as we have seen with Edmund, some service users prefer to get everything done in one go. Service users with complex health needs may also see a number of different health professionals, resulting in a preference to keep the number of appointments they need to a minimum, thus reducing their burden in terms of time, transport and parking costs, and possibly stress or anxiety associated with health consultations (see *Anxiety, embarrassment and gender related to health encounters healthcare* below).

Having another person in the consultation, although the consultation is potentially more complex, can be more efficient and more effective. According to the data from the current study, family members or a health facilitator who knows the person over time, facilitate the health professional’s agenda of gathering health information, making a diagnosis, formulating a treatment plan and communicating it to the service user (see *Role of the other in health consultation experiences*). However, if the health professional does not involve the service user in the consultation, this can alienate both the service user and their companion, making the consultation ineffective. Family members have been found to promote the personhood of the service user generally, although sometimes they collaborate with the health professional by reducing the number of agendas expressed, in order to promote the credibility of the service user and optimise the relationship with the health professional (see *Informal support*).

The current study suggests that the length needed for a consultation depends on several factors which are summarised below (Table 14: *Factors affecting consultation duration*).

<b>Table 14: Factors affecting consultation duration</b>	
<i>Factor Affecting Consultation Time Needed</i>	<i>Where Evidence Discussed/Derived</i>
Participant communication style – ability to express needs clearly helps to assess needs and address them more quickly.	Personal experience from interviews/ <i>Involvement in communication/inclusion</i>
Participant preference for involvement – dealing only with the carer can be more time-efficient, but can exclude the service user and risks missing important assessment information.	<i>Consultation length; Involvement in communication/inclusion.</i>
Length of relationship with health professional – knowing the person better makes it easier to focus on key issues more quickly, and gives the person security to address other issues at a future consultation.	<i>Individual personality/relationship with health professional.</i>
Previous health checks	James and Rolf both had long consultations while the health professional asked lots of questions, when annual health check template first used. Length of consultation did not increase satisfaction, as consultation led by information needs of healthcare provider rather than responsive to service user/carers concerns.
Expectations of service user	Daniel and Matt aware of limits on health professional time; Bissell et al., 2004.
Complexity of health need	Where service users have long-term illnesses such as diabetes, epilepsy, cardiac disease, they require specific as well as generic health monitoring, advice and management, particularly when they are not stable, e.g. Edmund ( <i>Listening</i> ); Ann ( <i>Role of the other</i> ). Consequently, there are more health assessments to make in the consultation, with the potential to make it longer. This is sometimes managed by having more consultations, possibly with a number of different health professionals (but could lead to fragmented care, hence need for parent/health facilitator).

<b>Table 14: Factors affecting consultation duration</b>	
<i>Factor Affecting Consultation Time Needed</i>	<i>Where Evidence Discussed/Derived</i>
Role of other	Particularly a family member or health facilitator who knows the person well can provide the information needed by the health professional to take a history, make a differential diagnosis, plan and manage interventions (See <i>Role of the other in health consultation experiences</i> ). If the professional carer does not know the service user well enough to act as health advisor, it could make the consultation longer as the health professional would find it difficult to gain the information needed to achieve a satisfactory medical outcome (see <i>Formal support</i> ).
Satisfaction with communication/relationship with health professional	Daniel's inability to ask questions; Daniel and Matt's awareness of time constraints on doctor; but actual time not necessarily consistent with perceived time (Ogden et al., 2004),

In their review of literature relating relationship and communication skills to efficiency in medical encounters, Mauksch et al. (2008) identified the importance of relationship-building and maintenance through “small talk”, although that is a behavioural expression of the concept of sharing the person’s lifeworld perspective (Mishler, 1984). In view of the patient’s ability to know when they were being respected by the doctor (Beach et al., 2006), this would only be effective if it reflected a genuine interest in the person, rather than a simplistic consultation strategy. Nonetheless, their identification of the need to build and maintain a relationship, ask open-ended questions to identify patient agendas and then explore them from the patient’s perspective, shows that focusing purely on a medical agenda can be inefficient and suggests that the time taken for a consultation is less important than the service user and carer feeling secure, listened to and involved in the consultation. Given that people with learning disabilities may take longer to formulate their thoughts in order to respond to questions or information, tolerance of silence by both the health professional and, where applicable, the companion in the consultation, may be required to allow the service user to contribute to the discussion. However, it can be stressful for the service user, as this may not be socially normal – hence the importance of both health action planning and assertiveness training. It has already been seen that service users in the current study did not discuss health action plans, but this shared planning and

documentation approach would help service users to express their needs and allow health professionals/health facilitators to check their understanding and ability to consent to tests and procedures. While discussion groups involving a variety of health professionals, goal-setting and keeping health diaries might seem a resource-heavy investment, it may be necessary in order to promote communication between service users, their carers and a variety of health professionals. The health facilitator role, and the study of health promotion classes that involved different professionals (Murphy, 2012), both demonstrate the importance of strategic liaison and multi-professional team-working to improve mutual understanding.

## **Embarrassment, Feeling Shy, Labels within Learning Disability, Presentation of Self, Credibility**

### ***Anxiety, Embarrassment and Gender Related To Health Encounters***

Many of the participants in the current study experienced some form of anxiety related to healthcare, although the triggers and expressed cause of that anxiety varied from difficulty in parking the car before appointments (see Tony's experience in *Informal support*), to injections or venepuncture; from physical examinations, to possible health worries; from seeing a new doctor, to having their accommodation changed against their wishes, or being unable to express fears (see Daniel in *Expressing agendas*).. Similarly, Penny had not told her practice nurse that she felt sick before going for a blood test:

Penny: *I don't like...blood tests [....] Make...make me sick. [....]*  
H: *Mm. Mm. Do you think about it before you go?*  
Penny: *Yeah.*  
H: *How long for? That day or the day before?*  
Penny: *Day before. [....]*  
H: *So how does it make you feel?*  
Penny: *A bit scared. [....] I've not...not told them.*

Penny's anxiety about the blood test, combined with her past experience of an unexpected and painful smear test, makes it understandable that she doesn't "*like the doctor*", and even though there is one female doctor who is nice to her, she still feels "*shy*" and relies on her carer to talk for her. Similarly, Daniel is unable to explain why he is so "*shy*" of the doctor that he cannot express his fears. James does worry about his health, since he has a genetic disorder that causes growths and tumours leading to epileptic seizures, reduced renal function and other disorders that affect his daily life and increase his risk of ill health, but he believes that doctors and nurses do all they can to help him. Paul

finds the worst aspect of his health check to be “*the needle*”, and does not like going for his health check, especially because he always has to wait while the health professional is talking to someone else, and the waiting makes him more anxious. Lisbet’s main advice to healthcare professionals, to make the health check better, is to “*get a good vein*”. Grace said she does not “*do needles*” and experienced greater anxiety than usual when a student nurse took her blood, because it took her longer, although she did not actually feel the needle go in, and Rachel hates the sight of blood, so also cannot watch the procedure. Lindsey also does not like needles, but has to have B12 injections and blood tests on a regular basis, and the last time she was left with a big bruise on her arm. Tony also does not like needles, and Ann needs someone to hold her hand while she has an injection, because she is scared. Edmund, who has autism and type I diabetes, explains:

*Edmund: I’ve always been petrified of needles. Scared ooh...there was a time when I was a kid I’d even pass out. I was absolutely petrified, do you know what I mean? I don’t know if it could be to do with my autism because obviously it’s a touching thing as well, if you know what I mean? A lot of [...] people who’re autistic are very, very sensitive to touches and feelings. It affects our brains very [...] differently to others. And touching something like that could probably make someone with autism jump and it might make ’em a bit [...] offended [...] Might scare them a bit [...] but I...I’ve matured an awful lot. I’m better with needles now than I ever have been but it’s always...it’s always been a phobia that I still can’t take blood yet from me finger to monitor me blood sugars.*

Despite this anxiety, however, Edmund still prefers to get his blood tests done at his regular appointments, partly because it reduces the number of times he needs to attend, and partly because he knows the person who is taking the blood. There is a higher incidence of related illness such as epilepsy in people with learning disabilities (Lindsey, 2002), requiring blood tests. Added to the need for regular health checks, this can contribute to an intrusive and unpleasant experience of healthcare surveillance that, unless it is tailored to the needs and wishes of the individual, can disempower and objectify the person (McIntosh, 2003). Blood tests are often seen as routine by a health professional, but for many of the participants in the current study they are a source of fear and anxiety. This is supported by a study that included focus groups of service users with a range of physical and intellectual disabilities ( $n=23$ ). They identified five themes related to their experiences of healthcare (see Table 15: *The Valued People project*) including a fear of needles and of pain.

<b>Table 15: The Valued People Project: Users' views on learning disability nursing</b>
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(Gates, 2011b, p. 18)
• The right kind of person
• Healthcare staff
• Some things worry us
• Specialist NHS staff
• Making things better

Other fears were around situations where they had less control, such as in ambulances or in hospital, where they might be unable to read or understand information and they might forget to tell staff about important needs, such as allergies. The anxiety caused by the association of needles with health consultations can lead to extreme avoidance of situations where needles are involved. For Edmund, his fear of needles prevented him from attending health check-ups and taking control of his diabetes, resulting in serious illness.

As well as her fear of needles, and her distress when the practice nurse told her she needed to lose weight or it could cause heart problems (see *Lifestyle advice can be aversive*), Rachel experienced severe anxiety when she attended for a mammogram:

*Rachel: I don't know, I was terrified, but... I was frightened of going in the room and taking my top off (mmm)... I was! I was frightened... "I hope I'm all right! I hope I'm all right!" And I was worried all the time... And the next minute, I had a letter, and it said I was all right.*

This experience was identified in a focus group study of women with learning disabilities ( $n=19$ ) who had experienced having a mammogram and also identified the need to undress as embarrassing. Additionally, some feared the machinery and not understanding what was happening (Truesdale-Kennedy et al., 2011). Like Rachel, they expressed a feeling of relief from worry once they received a letter saying that no cancer had been found. Rachel also finds any examination unpleasant:

*Rachel: [...] I don't like anybody prodding around.*  
*H: So, you don't want to be examined?*  
*Rachel: No!*

The anxiety identified here by Rachel about removing clothes and being examined was expressed by a few of the women participants:

*Lindsey: If the doctor asks me... to check me out... I get very uncomfortable... When I get me trousers halfway down... I don't know why.... Just makes me nervous.*  
*H: It makes you nervous. Why do think that is?*  
*Lindsey: I don't know, I just think "He's a man"*



Although they did not seem to mind male doctors carrying out other aspects of the consultation:

*Mandy: I don't mind if I'm examined by the nurse, or a female doctor, but I get a bit nervous say if I have to be examined by a male doctor. That's why, when I make my appointments, I ask to see the nurse, or a female doctor really. I don't mind male doctors talking to me, or taking blood pressure....*

Some of the participants, mainly women, not only felt anxious about their consultations, but were also embarrassed about their anxiety and therefore unable to express their psychological discomfort to health professionals, notably doctors. Lindsey noted that a doctor did not like her to say that she is embarrassed to be examined by him because he is a man (see *Involvement in communication/inclusion*). The anxiety experienced by Penny regarding smear tests, resulting from a painful experience causing bleeding, and where she had been given no preparation or information about the procedure, may not be an isolated incident. A study of women with learning disabilities who were interviewed about their experiences of cervical smear tests ( $n=52$ ) found that some had experienced discomfort related to having a larger speculum, and that some had been unprepared for the experience, and had been too tense for it to be carried out, or had needed a lot of support. Many of the women had also felt embarrassed and would not want to have a smear test carried out by a male health professional (Broughton & Thomson, 2000). Similarly, most women with learning disabilities expressed a preference for a female doctor for contraceptive health consultations (McCarthy, 2009). When James was embarrassed at the advanced nurse practitioner's use of the word "boobs" when she was examining his breasts and teaching him how to do it himself, he did not tell her that he felt embarrassed:

*James: I just got on with it. Inside, I was embarrassed, inside, deep inside, but I just got on with it, you know, I didn't want to show it in me face in front of "The Nurse", because she could tell by the looks on my face I would be embarrassed*

Another male service user with diabetes finds it difficult to discuss any problems with his "genital area" with health professionals, especially if he does not know them. On a weekday, he would ask his male health facilitator for support, but at the weekend, he would ask a male family member who also has diabetes.

Catherine, who generally expresses satisfaction with her healthcare, also commented that she would find it "very difficult" to say no to seeing a doctor or nurse if she didn't like someone, for example, if it was a man and she wanted to see a woman, a

finding echoed in the primary care evaluation study by Perry et al. (2013). Penny found it embarrassing to have to discuss the nature of her intimate relationship with her partner with the doctor:

*H: Was there anything you ever wanted to talk about and didn't?*  
*Penny: Get embarrassed [....].*  
*Health Facilitator: What do you get embarrassed about?*  
*Penny: Talk about there and them [....] Me and (partner's name) f...friendship [....]*  
*Health Facilitator: Do you tell them that you get embarrassed?*  
*Penny: Yeah. Don't listen to me [....].*  
*Health Facilitator: What makes you feel embarrassed talking about your friendship with [partner's name]?*  
*Penny: Say what you doing every night. I say kiss and cuddle, that's it. You have...you have sex have you? No [....].*  
*H: Is it embarrassing to talk about sex?*  
*Penny: Mm [....] I said...I said to doctor no!*

The examples above are not only about heightened anxiety related to health consultations; they also show the premium that service users place on how they are seen by the health professional. The possible loss to their self-esteem that might result from them being seen as sexualised, demanding, anxious or even less acceptable by virtue of their cognitive disability could result in a fear of expressing basic needs or feelings that are important to effective healthcare consultations, for fear of being seen as less credible by the health professional. There is a clear sense of embarrassment associated with situations where their backstage persona is revealed to the very person by whom they want to be seen as credible (Goffman, 1959), resulting in a heightened sense of embarrassment and fear of embarrassment associated with the health consultation. This suggests that some participants in the current study, feel discredited within the health consultation, possibly by virtue of their learning disability, and sensitive issues related to their sexuality, mental health and related disorders (including epilepsy – see *Psychosocial healthcare/needs/labelling and stigma* below). Goffman (1963) suggested that stigmatised people (by virtue of their difference to the socially desirable norms) offend against norms of identity or being. These “defects”, which they are unable to correct, are therefore discrediting, so by extension, any health encounter risks making the person with learning disabilities feel discredited by their disability. However, he argued that the process of agreeing on what was discrediting was one that occurred within a relationship. While Goffman (1961) suggested that people with a mental illness were “funnelled” into that role through various processes of institutionalisation within asylums, it is possible that some people with learning disabilities may perceive a similar process in their health encounters,

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and may adopt different strategies to avoid being discredited. In the current study, some service users disengaged from health consultations, allowing relatives or carers to engage on their behalf, while others discussed their feelings outside the consultation, seeking to restore a more positive self-concept. The role of the companion in promoting their personhood and enabling the health professional to respect them as an individual was central to this process. (see Chapter Four *The role of the other in health consultations experiences*). Women who attended consultations related to unexplained chronic pain described a variety of strategies aimed at fitting into normative biomedical expectations in order to be seen as credible by the doctor, and therefore have their symptoms taken seriously, fully investigated and managed, and avoid damage to their self-esteem caused by not being believed (Werner & Malterud, 2003). Thus, while health professionals may see the use of slang words as easier to understand for people with learning disabilities, some service users, like James, may see it as embarrassing because it conflicts with their view of being seen as a credible person who is able to use correct (maybe even proper) language. Similarly, women with learning disabilities in the current study show awareness of social inhibitions related to their sexuality, which conflict with undressing to be examined by male health professionals, or discussing their needs related to sexual and reproductive health. As discussed in *Involvement in communication/inclusion*, Penny has previously experienced an unexpected and painful smear test, that was not explained to her beforehand, and she is now so anxious about them that she feels upset if a doctor brings it up in consultation, or if she receives a letter about it. Penny is aware that the smear test is to check for cancer, and her embarrassment over talking about her own sexual activity and her fear of the smear test could be related. Whatever the reason, her embarrassment prevents Penny from discussing sex openly with her doctor, even though she says she finds her female doctor friendly, which could reduce the effectiveness of healthcare she receives in this area. This kind of anxiety, related to loss of self, is not easily overcome simply by habituation, but depends on a perception of being accepted and valued by a health professional whose authenticity, empathy and unconditional positive regard can be trusted.

Most of the literature addressing anxiety in medical encounters focuses on anxiety as being either a medical illness in itself, or pertinent to a specific disorder. Thus, papers investigating anxiety can be found for patients with existing anxiety disorders or medically unexplained symptoms (Peters et al., 2009), psychiatric co-morbidity, such as post-traumatic stress disorder, or patients with symptoms or a diagnosis of life-limiting disorders, such as cancer (Smith et al., 2011) or cardiac disease (Gordon et al., 2008).

Indeed, the medical diagnostic label of hypochondriasis may be replaced by the term health anxiety, thought to be less stigmatising and more precise (Fink, Ørnbøl, & Christensen, 2010). However, this increases the potential for medicalisation of “normal” anxiety, with the chair of the *Diagnostic and Statistical Manual of Mental Disorders (DSM)-IV* (American Psychiatric Association, 1994) criticising the latest guidelines (American Psychiatric Association, 2013) for their potential to label many people with unexplained medical symptoms as mentally ill (Frances, 2013). In a study of adults with learning disabilities in Scotland ( $n=1023$ ), only 3.8% were found to have a recognised anxiety disorder, compared with a calculation from the literature of 6.9% in the general population (Reid, Smiley, & Cooper, 2011). Thus, anxiety about health consultations is likely to be reactive and situation-specific, rather than part of an existing psychiatric disorder. Where anxiety is accepted as a common response, as with a cancer diagnosis, research has shown the importance of person-centred approaches in reducing anxiety and enhancing communication. For instance, in a multi-group comparison study, videos in which oncology consultants enacted different recommendations for the treatment of breast cancer were shown to randomly-assigned women ( $n = 220$ ), both breast cancer survivors and those who had not had breast cancer. The videos differed by 40 seconds (out of an 18 minute consultation), producing a standard version and an “enhanced compassion” version (Fogarty, Curbow, Wingard, McDonnell, & Somerfield, 1999, p. 373), in which the consultant empathised with the concerns of the patient, touched her hand and emphasised partnership in combatting the illness. Although all participants experienced significantly higher anxiety levels after watching the video, those in the “enhanced compassion” group had significantly lower post-video anxiety levels than those who had seen the standard video. They also found the doctor significantly more compassionate and were more likely to believe the doctor cared about the patient (Fogarty et al., 1999). This highlights the importance of empathy and compassion to establish trust in a cancer diagnosis scenario, but the current study suggests that many service users with learning disabilities experience heightened anxiety before even routine health consultations. This suggests they may require enhanced awareness of their feelings in the consultation, and an emphasis on compassion and the development of a trusting relationship by the health professional, in order to overcome the barrier of anxiety and improve disclosure and concordance.

Videotaped GP consultations in Norway ( $n = 1388$ ) showed that patients with high levels of anxiety prior to a consultation (one-third of the participants) seldom expressed the cause of their anxiety and were more likely to be female, less well-educated and have more

negative indicators of physical ill health than patients with low anxiety levels (Bensing, Verheul, & van Dulmen, 2008). The length of their consultation averaged almost two minutes more than that of patients with a low anxiety score, and, as well as requesting more referrals and prescriptions, they also revealed a great deal more psychosocial information (Bensing et al., 2008). This suggests that people with learning disabilities may be more likely to experience high anxiety related to healthcare, relative to other service users, even without the additional sensitivity of people with autism, although more specific research is needed to address this question. Given the finding by Reid et al. (2011) that generalised anxiety is less frequent for people with learning disabilities than in the general population, this suggests that health consultations and interventions are a specific cause of anxiety. In the current study Mark did not tell the doctor about his worries over his coughs and headaches, but said he would if she asked him about them, and Owen found being “told off” about his weight unpleasant (*Lifestyle advice can be aversive*). The Valued People project service user study found that communication was sometimes problematic, and that service users wanted the health professionals who looked after them to have some knowledge of or training in caring for people with learning disabilities. This was supported by my own experiences when interviewing service users, in which I identified the importance of experience, reflection and sensitivity to the communication needs of people with learning disabilities (see *The interview experience – personal development, barriers and insights*). Certain experiences, particularly of ambulance transport and emergency care, were quite frightening for participants, and they needed more time, help and communication to help them to understand what was happening and cope with things that made them anxious, such as needles (Gates, 2011b). Additionally, however, their anxiety may have been caused by the fear of being perceived more negatively within the health consultation because of their disability (see *Psychosocial Healthcare / Needs / Labelling and Stigma*). The negative experiences of participants in the current study, sometimes from many years ago, suggest that they have been sensitised to potential threats to their physical, psychological or social well-being related to health professional encounters in the past, which have affected their current perceptions. Anxiety about the possible reactions to and consequences of health assessment can be sufficient to prevent engagement with the health professional, and therefore disclosure of health concerns or concordance in health goals and behaviours.

### ***Strategies to Reduce Anxiety***

Some participants were able to explain their anxiety, and strategies that they and health professionals used to overcome it, in more depth. Elaine was very anxious when she met a new GP, and was upset when, at first, he did not talk to her, but did to her mother. Her mother, however, realised that the GP did not realise that Elaine could talk so told him to ask Elaine what her name was. Once he did, and realised that Elaine could talk, Elaine was able to overcome some of her anxiety of meeting new health professionals. Some of Elaine's anxiety was caused by her previous experience of staying in an acute treatment and assessment unit, so when that was closed down and a new centre was opened in its place, Elaine was invited to interview the new health professionals:

*Elaine: Yeah which I interviewed the people for there.*  
*Health Facilitator: Yes you have done, you've interviewed people for there and you're very good at it aren't you?*  
*Elaine: And I think it's a much better place in there because I've been in there, I've met the staff and when I've had any medication, dinner time medication, when I've been there, they've done it.*

Elaine's sense of involvement in recruitment has enhanced her feelings of control and self-efficacy in the situation, so that she is less anxious and more confident that any short-term care needs she has will be managed competently and consensually. By showing Elaine that her choice is valued, her anxiety has been reduced. Although Penny is anxious about being examined by the doctor due to her past experiences, her current friendly female doctor explains what she is going to do before examining her, and her carer will ask questions for Penny, to make sure Penny understands the doctor. The doctor does not offer Penny a smear test, because of Penny's anxiety, although Penny still feels anxious when she receives the written invitations for one. Although Penny has not fully overcome her anxiety, as she has not told the doctor of her fear of having blood taken, and she has not been open with her about her sex life "*cause I get embarrassed in doctor*", she seems to be building some trust with her new doctor. Penny was also anxious because she sometimes felt her heart beating really hard, so she went to the practice nurse, whom she knew and liked, for an electrocardiogram, and was reassured that her heart was normal. Anxiety has been identified as a factor in health encounters in a large scale evaluation of health services by people with learning disabilities (Gates, 2011b), and in the study by Perry et al. (2013) anxiety was seen as a barrier to communication, with cervical smears, breast examination and needles all causing significant concern, both at the time and until the results were received. This could have a significant impact on the willingness and ability to engage with

the health professional and communicate within the consultation. For example, Penny also had raised blood pressure due to her anxiety about seeing the doctor:

H: *So do you have...have you had your blood pressure taken a lot?*  
Penny: *Yeah. It's been dead high.*  
H: *And did it come down?*  
Penny: *Mm.*  
H: *Because you were less worried?*  
Penny: *Mm.*  
H: *So what...what do you do to stop being worried now?*  
Penny: *Calm down.*  
H: *How?*  
Penny: *Calm...(makes noise) yeah.*  
H: *Do you think nice thoughts?*  
Penny: *Mm.*  
H: *What do you think about?*  
Penny: *About the weather.*

A combination of regular visits, seeing the practice nurse and using distraction techniques has reduced Penny's stress response when she has her blood pressure taken so that it is now normal. She, like Edmund, Jonathan and Elaine, is always seen by the practice nurse at the beginning of the session, so that she does not have to wait or feel overwhelmed by a lot of people and noise, which would raise her anxiety. Jonathan becomes worried if he does not understand his healthcare, so he needs to understand his medication and, like Elaine, needs to know that he will receive it. He achieves this by self-administration, but also by raising any concerns he has over his medication or (as seen in *Expressing agendas*) by seeking information so that he can be involved in decision-making.

Edmund has also found habituation and distraction useful techniques to overcome his anxieties related to touch and venepuncture. He sees the same practice nurse and health facilitator, and he engages in conversation with them while having his blood taken:

Edmund: *I will never get over the phobia. I think...I think...I think obviously there comes a time when you...when you're going regularly it's like a routine really. Something...you get used to it[...] I don't think about it as much. Like if I'm having...having it done (the health facilitator) who I work with will just start talking to me to keep my mind off it and I think also not looking at it I think helps as well. 'Cause I think the more you worry about it I think the more it's gonna hurt.*

He also described how he learned to administer his own insulin injections:

Edmund: *....just watching my dad quite regularly really and obviously sitting down, experiencing it myself. Without putting the insulin in me I just like, a few times a day, just put the needle in me, just to try and gain a bit of confidence.*

Edmund, his health facilitator and practice nurse have worked together very closely to enable Edmund to manage his own diabetes because he was admitted to hospital due to not managing his diet and insulin correctly. Edmund wants to gain control of his diabetes, which is also related to his mental well-being (because Edmund also has mental health input) and to his social well-being (he has a young family, but is separated from them at the moment). Edmund has identified that he believes that, if he can overcome his phobias and gain control of his diabetes, this will help with the rest of his life, giving him a strong motivation to work with his health professionals. He finds that discussing what is going to happen, and then having the consultation explained to him by his health facilitator, is helpful in reducing his anxiety. However, he is still anxious about seeing his hospital consultant, and thinks that he and his health facilitator will be tackling this next. The trust in his health facilitator, combined with knowing his practice nurse, has enabled him to start gaining confidence in health professionals and begin to overcome his phobia of new people, but he is still dependent on his health facilitator to enable him to achieve this.

Edmund's phobia prevented him from engaging with health services and managing his diabetes until serious illness led to his health facilitator and practice nurse initiating a programme of graduated exposure supported with a picture chart to show how his blood sugar levels progressed. A case study involving a man with autism and learning disabilities, whose anxiety about needles was so great that he was unable to even attend health clinics without being sedated, showed how he was able to attend and voluntarily tolerate a needle on his skin (Wolff & Symons, 2013). This was achieved through graduated exposure to needles and behavioural reinforcement, starting at home with sight of a syringe at a long distance, and ending in a health clinic with the needle to skin. A key point, though, is that following this successful intervention to address his needle phobia, he was able to "fully participate in regular medical examinations and office visits without sedation" (Wolff & Symons, 2013, p. 347).

A more explanatory approach, which gave a woman with autism control over the graduated exposure process, was used to help her overcome her needle phobia (Edwards & Northway, 2011). In this instance, photographs were used to explore "Sara's" feelings about health visits, and pieces of equipment were available for her to hold. Eventually, Sara was taken to the clinic in a less busy period (as previously identified, noise and new faces can stimulate increased anxiety in people with autism) and, with her permission and under her control, a tourniquet was applied. The first time she had blood taken, Sara was given both a sedative and EMLA cream (a local anaesthetic cream, applied by her father an hour



prior to the blood test, giving it time to work). The second time, she was able to cope with just the EMLA cream and finally, she was able to have blood taken, in the hospital, and watch the needle entering her skin. This more holistic approach is both more ethically acceptable (the element of choice and control is diminished in the former, behavioural approach) and psychologically effective, because it ensured that emotional, cognitive and behavioural aspects of the experience were all addressed. However, both case studies demonstrate the significant impact that a needle phobia, and possibly other anxieties related to health consultations, can have on the person's ability to engage with the health consultation, and the positive outcome that reducing this anxiety and associated behaviour can have on the whole service user experience.

As identified previously, Rachel experiences acute anxiety when attending for a mammogram, which she related to both the discomfort of the procedure, having to get undressed and go into the room without her carer, and also fear of the outcome. Catherine, who is sanguine about this procedure, is part of a group of service users who go to meetings about health with other service users and talks about her experience, in order to reduce their anxiety about having a mammogram.

James' practice nurse reinforced the importance of him making an appointment to see someone in the practice if he was worried about anything, emphasising that nobody would ever say "*you shouldn't come here for that*". Strategies used to reduce the anxiety experienced by several of the participants are outlined in Table 16: *Strategies to reduce anxiety*.

<b>Table 16: Strategies to reduce anxiety associated with health consultations</b>	
<b>Participant</b>	<b>Anxiety Reduction Strategy</b>
<i>James</i>	<i>Valuing person and concerns – Practice nurse emphasises access and that his concerns will be taken seriously.</i>
<i>Penny, Edmund, Jonathan, Elaine</i>	<i>Waiting time reduction/calm waiting room – Seen at beginning of consultation session to prevent waiting and reduce the number of people in waiting room which can be noisy and disturbing, especially for people with autism.</i>
<i>Edmund</i>	<i>Habituation with needles, especially self-administration of insulin – starting off with watching, then just puncturing skin before beginning to self-administer.</i>
<i>Edmund and Penny</i>	<i>Distraction techniques – either being encouraged to think of other things (self-management) or being involved in a conversation to prevent them from focusing on injections or venepuncture.</i>
<i>Elaine, Penny, Edmund,</i>	<i>Sense of control gained from: predictability, involvement</i>

<i>Jonathan</i>	<i>and trust – through explanation of procedures, involvement in decision-making about their own health and involvement in employment procedures (interviewing staff) for specialist services.</i>
<i>Catherine</i>	<i>Role-modelling – Helps reduce anxiety in others by relating her own experiences of having a mammogram.</i>
<i>Penny</i>	<i>Avoidance – doctor does not raise the issue of smear tests in order to develop a more trusting relationship with Penny.</i>
<i>Elaine, Jonathan, Edmund, Penny</i>	<i>Trusting relationship – their past experiences have resulted in a lack of trust in health professionals, so they need to feel that they have a relationship with someone they know, so that they can ask questions and express their feelings without it harming the way they are seen. The practice nurse and health facilitator work together to ensure that they feel secure in consultations. Regular visits with the same health professional is part of this.</i>
<i>Elaine</i>	<i>Carer support in consultation – Mother encouraged doctor to talk to her. Carers can support health professionals to gain confidence in interacting with someone with learning disabilities.</i>

### ***Psychosocial Healthcare/Needs/Labelling and Stigma***

While people with learning disabilities may be supported to overcome anxieties about specific procedures, the feelings of embarrassment experienced in relation to health encounters are more difficult to understand and address. Early in the data collection process, Matt talked about his experience of feeling a loss of control over his life, due to having been moved to different accommodation with little notice, and his difficulty in negotiating his needs with health professionals (physiotherapy for his knee) and finding his psychiatrist “*rather stern*”. Both Matt (see *Expressing agendas* and *Multiple service providers*) and Lindsey (see *Expressing agendas* and *Informal support*) had experienced communication problems with their health providers that had led to a lack of trust between them, their carers and the health professionals. This alerted me to the possibility that people who used multiple services, particularly mental health services, might have difficulty in presenting themselves (or being presented by their relatives) as credible participants within the health consultation. According to Werner and Malterud (2003, p. 1410), “Doctors find consultations with medical uncertainty, interpersonal difficulties, chronic and so-called unexplained disorders difficult to manage”. This was echoed by my own experience, within the last two years, of being asked by a junior doctor why people with learning disabilities cannot have their health managed by specialists in that field. The complexity and long-term care needs of people with learning disabilities, especially those with additional physical and/or mental health needs, can lead to them becoming a

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“heartsink” patient, due to the number of agendas that need addressing (Barry et al., 2000, p. 1248). As discussed earlier, Mark’s mother not raising his concerns about his headaches (see *Informal support*) may have been related to her managing the presentation of Mark and herself in order to promote a good relationship with the health professional and optimise his health outcomes. Although participants were asked if they felt doctors or nurses could help with emotional problems or difficulties with friends or families, only participants who used mental health services were able to identify specific ways in which they could do this, for example, when Jonathan asked for help after his bereavement (see *Expressing agendas*). This suggests that they do not have experience of psychological or social support from health professionals unless they have an identifiable need for a referral to specialist services. Having identified possible negative effects of complexity and mental health disorders for some participants, towards the end of the data collection I recruited some participants purposively who used mental health services, or who had a diagnosis of epilepsy.

Epilepsy seemed to be significant because the service users who mentioned it seemed reluctant to talk about it (James and Simon) or suggested that they did not have epilepsy any more because they did not have major seizures (see Roddy in *Expressing agendas*). Epilepsy has been felt to be a highly stigmatising label by people with epilepsy, conferred on them by doctors, and one that is generally hidden in order to prevent potential discrimination (Scambler & Hopkins, 1986). Catherine, however, when asked about other illnesses, was quite open about having epilepsy:

*Catherine: I did used to have fits but I had fits years ago....Fell on the floor everywhere but I grew out of them.... I don't have those any more now. It wasn't nice.*

Ann also had epilepsy, but records of her seizures needed to be kept by her paid carers, and had been requested by her GP (see *Formal support*). Ann was worried about her epilepsy, and identified that she wanted her doctor to find out why (from her perspective) they were getting worse:

*Ann: I want... I want the doctor to do any tests*  
*H: What tests do you want him to do? What do you want him to find out?*  
*Ann: About... About me fits again*  
*H: About your fits... So you want them to find out more about your fits?*  
*Ann: Yeah*

However, neither she nor her carer had asked about it at her last health check, although Ann had great difficulty in expressing her thoughts verbally, often taking a long time and

having difficulty in explaining herself (see *Explanations and understanding in health consultations*):

- H:            *Yeah. So when you went to see the nurse for your check-up, did you ask her why your seizures were getting worse?*
- Ann:        *(long pause)*
- H:            *Did you ask her any questions?*
- Ann:        *No*
- H:            *Did CT ask her any questions for you?*
- Ann:        *No*

Epileptic seizures are a very public manifestation of ill health and disability for the person with epilepsy . They can cause urinary incontinence and loss of consciousness, with people often being taken to hospital for something that they are used to managing themselves or that their carers would normally manage at home. Health "crises" resulting in tests, hospital admissions, changes in management, may presage a downward trend in the trajectory of illness (Corbin & Strauss, 1991), bring back memories of previous acute healthcare experiences and result in increased anxiety levels. For example, Ann stated a desire to see her doctor more frequently and was anxious about her increased seizures. A prospective correlational study of 244 adults with epilepsy in California, using a stigma scale and an epilepsy self-efficacy scale, as well as 5-scale questions regarding worry about seizures and social support, found that strong stigma associated with epilepsy affects self-efficacy, with self-efficacy and perceived social support decreasing, and worry about seizures increasing with felt stigma in people with epilepsy ( Smith et al., 2009). Ann's fears about her future health would have affected her feelings of self-efficacy, and the concerns her health professional expressed about the need for more consistent recording of her seizures could also have undermined her feelings of social support. A lack of perceived social support is thought to be less effective in moderating the effects of stress on physical health, leading to poorer health outcomes, compounding the existing health inequalities associated with having learning disabilities (Emerson et al., 2012)

This sense of stigma is echoed in James' expressed concern that his employers now have to contact his carer whenever he has a "*fall*" at work (which seemed to be a euphemism for seizure). James has a full-time voluntary post that he really enjoys, and he values his independence. He was reluctant to disclose his "*falls*" within the consultation, having to be prompted by his carer, and seemed to perceive his epilepsy as a threat to his independence and self-efficacy). Scambler and Hopkins (1986), in their interview study of people with epilepsy (*n*=94), found that being given a diagnosis of epilepsy was, in itself, so

alarming and perceived as a negative label, that people often tried to negotiate the condition to a different diagnosis or label. This was ascribed in the study to the importance of the doctor as legitimising the label, and to the stigma attached to that label as perceived by their participants. This perception of stigma was often based on learned responses from parents not to use the word epilepsy or talk about it outside the home, and resulted often in attempted concealment of the condition from others, including employers and partners. The percentage of people who experienced enacted stigma in these situations (where they were actively discriminated against due to disclosing their epilepsy diagnosis) was relatively low, at less than a third having experienced relationship breakdown following disclosure, and 29% having experienced casual discrimination at work. However, 72% of people in full-time employment did not disclose their condition, and 67% of those with a diagnosis before marriage had not disclosed full information about their diagnosis and seizures. This was attributed to both a sense of shame and a fear of encountering enacted stigma (Scambler & Hopkins, 1986). This burden of concealment for the person with epilepsy of “managing information about his failing” (Goffman, 1963, p42) in order to prevent their discreditable identity from becoming a discredited one, which is known by others, was found to be “more disruptive of the lives of people with epilepsy than enacted stigma” (Scambler & Hopkins, 1986, p38). The current study identifies the way in which past experiences of feeling less valued within health encounters has led to service users avoiding disclosure of potentially discrediting attributes, including their own communication difficulties, suggesting a powerful link between anticipated stigma and withdrawal from engagement in health consultations.

These conclusions are echoed in a more recent phenomenological study of 30 adults with epilepsy by Kılınç and Campbell (2009), which found that people with epilepsy sometimes avoid disclosure of their epilepsy, and that this seems to be related to embarrassment felt due to having epilepsy. Although they identified that most stigma experienced was felt stigma (possibly a sense of embarrassment or ignorance in another person) rather than behavioural stigma (being treated differently to other people), it nonetheless led to people making significant adaptations to their life in order to hide their epilepsy from other people (Kılınç & Campbell, 2009). So, there seem to be a number of factors inhibiting communication about epilepsy, from a feeling that the seizures are no longer an issue, to an avoidance of a source of embarrassment and anxiety. The combination of a fear of a downward trajectory of illness with epilepsy and a fear of felt stigma mean that discussion of apparently simple issues, such as the number or type of

seizures a person experiences, may raise feelings of embarrassment and anxiety for the service user. These feelings can make it difficult for the person to confide in and openly discuss their feelings about and experience of epilepsy with the health professional, and could lead to under-reporting of seizures and sub-optimal management of the condition.

(Charmaz, 1983, p177), in her grounded theory interview study of people with long-term illness ( $n=57$ ) found “(e)xperiences of being discredited, embarrassed, ignored and otherwise devalued also contribute to the growing isolation of ill individuals and to their subsequent reappraisals of self.” She identified the ways in which people with long-term illness start to see themselves as of less value than, and a burden to, other people. In this way, they cease to negotiate a positive self-concept and accept a “discredited self” (Charmaz, 1983, p188). Matt and Daniel both identified their belief that people with learning disabilities were not welcome in GP practices, due to the cost of treating them:

*Matt: The cheapest way is to give me a prescription for some gel which doesn't work, and that, you know... You know what I mean?*

*[....]*

*Daniel: Can I just put a word in... We're not....Not welcome... And do you know... And d'you know why we're (indistinguishable)... It's the price.*

This perception is not unfounded, as evidenced by a radio report quoting a GP's written response to a letter from the managing director of a proposed care home for people with learning disabilities in his area:

*“Your letter gave me a sense of absolute dread and horror. Fortunately for both of us there is another practice, which also serves the \*\*\*\*\* area. I will be letting the Town Council know about your proposal. I can see nothing to be gained by you visiting the surgery.”*

(You and Yours, 2012)

It is highly likely that some of the participants in this study, those who were members of a self-advocacy group, were aware of some of these arguments and may have recognised a similarity to their own situations. Since the decision of whether or not the person is seen as discredited and accepts that identity is negotiated within the health consultation, any previous experiences of becoming discredited within health consultations could result in the person accepting that role, and seeing themselves as discredited; or in their rejection of that role, so that they either disengage from the health consultation

process, to avoid negative consequences for their self-concept and self-esteem. According to Charmaz (1983, p177), in her interview study of people with long-term illness:

“Experiences of being discredited, embarrassed, ignored and otherwise devalued also contribute to the growing isolation of ill individuals and to their subsequent reappraisals of self. Sometimes such episodes result in these persons' voluntary withdrawal from the scenes in which devaluation is played out...”

Other service users may have tried to engage and argue an alternative but, as shown in the member check, participants are aware of professional power within the consultation (Mishler, 1984), and may find it difficult to make their views heard, possibly resulting in being seen as uncooperative in their care. The importance of maintaining face as being a credible person to healthcare professionals, in order to avoid being embarrassed or even discredited, may increase the need not to disclose discreditable attributes, particularly for someone with learning disabilities. Participants tried to avoid disclosing attributes such as: having sex or even exposing the body for examination; having seizures (something denied by one service user, who was contradicted by his relative, but a common terminology of “falls” was used as a euphemism for them); having anxiety about health or healthcare; even asking for information. For people with learning disabilities, the potential for feeling discredited and fearing disclosure of discreditable attributes appears to be a peculiarly heavy burden, which inhibits their engagement with the health consultation process and adds an additional complex barrier to communication between them, their carer and the health professional.

Some participants, however, may not have felt discredited. Daniel, sees his male GP every year for a health check, finds him friendly and is satisfied with his healthcare, while Matt believes he has not received appropriate care for his knee, due to cost, and thinks he needs more time with the doctor, a sign of not feeling that his needs are addressed (see *Consultation length*). Matt sees a psychiatrist, whom he finds rather “stern” and has clearly experienced unsatisfactory consultations with health professionals. Simon has epilepsy and a psychiatric disorder, and does not like seeing the psychiatrist because he asks him how he is feeling, and it makes him think about his mother’s death, and also because the psychiatrist tells him he is “not well enough”, although he is satisfied with his annual health checks at his GP practice. Elaine is happy with seeing the practice nurse for health checks, as she and her family have known her for a long time. Elaine also fondly remembers the

nurse (specialist in learning disability and epilepsy) who has looked after her epilepsy most of her life:

*Elaine: I liked Sister \*\*\*\*\*. She'd known me since I was a little girl.... Since I was about three.*

*H: Ahh. So did you feel safe with her?*

*Elaine: Yeah. She used to weigh me and she used to say how good I was.*

*[....]*

*H: So were you sad when she retired?*

*Elaine: In a way but I would just like to know which nurse I...I...I've got in place.*

Elaine is very aware of the importance of being able to trust health professionals as she was admitted to a treatment and assessment unit as a young woman, and found it distressing:

*Elaine: [...]I hated it at \*\*\*\*\*. I was in there for six weeks. I really did hate it 'cause the nurses weren't nice to me at all [...]*

*H: How did they talk to you?*

*Elaine: Horrible. They wanted to like, when I was acting things out, 'cause I walk round in circles and talk to myself and repeat things, I was doing that and they were saying "oh she's doing this, she's doing that" and they didn't want to leave me on my own and at one point they were asking me to go to the shop but...and I didn't know the way to the shop and then they started following me around everywhere I went! 'Cause I told them I needed somebody with me. I couldn't go to the shop on my own 'cause I didn't know where I was going. I don't live in \*\*\*\*\* so I wouldn't have a clue. The people wouldn't know me. It was on a main road.*

Elaine finds it very positive that she lives in a flat with other service users and carers, and has gained some control over her life, enabling her to achieve a sense of adulthood and independence. However, her past experiences have made her wary of trusting new health professionals. She has a trusting relationship with the health facilitator who is able to act as her advocate and advisor in managing her healthcare. Jonathan has also found that he has been given more control in recent years. He had previously been a long-term patient in a secure treatment and assessment unit, but now lives in supported accommodation, next door to his girlfriend (see *Informal support*) and self-administers his medication. He has access to his care records in his living accommodation, discusses his concerns about his medication and healthcare with his health facilitator, and feels able to talk about them with his practice nurse. He has had negative experiences of doctors in the past (see *Involvement in communication/inclusion*) and prefers to feel in control of his health:

*Jonathan: I do...I get my own tablets out of me...drug cupboard.*



H: *Mm. So you're in control of it?*  
Jonathan: *Yeah.*  
H: *And do you feel that's good?*  
Jonathan: *Yeah.*  
H: *You like to be in control?*  
Jonathan: *Yeah.*  
H: *When you were younger did you feel in control....?*  
Jonathan: *No.*

For Matt, Elaine and Jonathan, trust in a benevolent, paternalistic health professional is not possible, due to their previous experiences, particularly of psychiatric care. However, provided all the health and social care professionals whom they encounter understand, and are sensitive to, their need to feel in control, they will co-operate and, over time, develop a relationship with them. For all three, though, their trusting relationships are with the health facilitator and the practice nurse, rather than with the doctor. Their previous negative experiences of doctors have affected their current feelings towards medical encounters, possibly because it is not possible for them to see the doctor without being seen as a person with a psychiatric disorder.

Approximately a third of people who had been diagnosed with mental illnesses, such as anxiety or depression, stated that they had avoided disclosing their psychological problems to GPs because they felt that they would not be sympathetic to their needs, or would prescribe medication that they did not want, or simply that mental illness was stigmatising and should not be discussed with anyone (The MaGPIe Research Group et al., 2005). A related study, also set in New Zealand, found that people with symptoms of mental illness were fearful of disclosure to the GP because of their perception that the doctor could have them "sectioned" and that they would lose control over their own life (Dew et al., 2007, p. 1066). A key factor identified to promote disclosure was trust in the doctor. However, as with the experience of the diagnosis of learning disability being found to overshadow health professionals' perceptions of physical health diagnoses (Michael & Richardson, 2008), people with schizophrenia have found that the label of having schizophrenia has resulted in their physical illnesses being seen as psychosomatic by health professionals in Germany. They even reported mental health professionals finding the attitudes of other health professionals condescending and marginalising (Schulze & Angermeyer, 2003).

Literature on issues that people are sometimes reluctant to disclose to their GP or practice nurse focuses mainly on sexuality (including reluctance to reveal homosexuality, adolescent sexual activity and incest) and on psychological concerns or mental illness.

Lesbian women may be reluctant to come out to their GP if they feel that their GP is not sensitive to different sexuality, for example by using gender-specific terminology related to partners. Another barrier is the fear that they will be regarded as a lesbian first, before their overall personhood and health needs are considered (Bjorkman & Malterud, 2007). Fear of disclosure of sexuality to GPs may be related to perceptions of GP attitudes, since a study of GPs in Sheffield found that they had difficulty in discussing sexuality or sexual health with patients (Hinchliff, Gott, & Galena, 2005). This seems to be supported by Penny's reluctance to discuss her sexual activity with her GP, even though she likes the GP. However, given the potential for control by others over the sexual expression and ability to bear children for people with learning disabilities (Rushbrooke, Murray, & Townsend, 2014), it is not possible to divorce this from other perceived social constraints (although Penny's relationship is fully supported by the staff involved in the care of her and her partner) or, indeed, her learned fear of smear tests (see *Involvement in communication/inclusion*).

Discussion of sexuality and sexual expression in people with learning disabilities may be hampered by perceptions of the person being child-like, vulnerable to sexual abuse and the fear that sex education may increase rather than decrease risks related to sexual activity, such as sexually transmitted infections and unwanted pregnancy (Barber, 2011; Rohleder & Swartz, 2009). Privacy and gender are also issues for women with learning disabilities, as in the study by McCarthy (2009), where most women were accompanied to sexual health and contraception consultations, and preferred this, but one was accompanied by a male carer, which she found embarrassing. One participant explicitly explained that she was advised by her GP to have a long-term implant because she was more vulnerable to sexual exploitation, but most did not ask questions, and the doctors generally did not ask them questions or check their understanding. The vast majority of women did not think they had a choice about having contraception and had it because other people told them they needed it; 18 women did not use family planning services, but had their contraception prescribed by GPs, who may have known them better, but were not specialists in providing this service. Even if the health professional is sensitive to the needs of the service user related to expression of sexuality, historical experience may lead to the service user proceeding cautiously and feeling able to trust the health professional before fully disclosing their sexual history and current situation. Conversely, access to mainstream contraceptive services seems to provide a more explanatory and non-

judgemental service (McCarthy, 2009), so the health facilitator could be an important bridge between the two.

Patients with medically unexplained symptoms often decide not to tell their GP about their emotional problems, partly because their relevance has not been explained by the GP, partly because they fear the GP will not explore their physical health as a result, and partly because they do not have a relationship within which such disclosure would be appropriate (Peters et al., 2009). In view of the difficulties that many of the participants in this study have either experienced in the past or still have around building a trusting relationship with healthcare professionals, notably GPs, this suggests that psychosocial issues may not be discussed in health consultations.

Thornicroft, Rose, and Kassam (2007), in their literature review of the factors leading to poor uptake of and outcomes from physical healthcare in people with a mental illness, argue that psychiatry is a marginalised speciality within medicine. This is supported by Paul's response when I asked him if the doctor he was talking about was a psychiatrist, and he said: "*No, a proper doctor*". Thornicroft et al. (2007) identify that medical students are already adopting stigmatising attitudes towards mental illness, with most reluctant to consider specialising in psychiatry. In addition, people with mental illness are found to have less access to primary healthcare, and receive inferior care for cardiovascular disease and diabetes, despite higher rates of these disorders, as well as obesity and HIV/AIDS. These factors combine to produce a higher mortality rate in people with mental illness than in the general population. Furthermore, experiences of being discriminated against and stigmatised by GPs and other health professionals, resulting in a lack of sympathy and even respect, make health-seeking experiences aversive (Thornicroft et al., 2007). This supports the data from the current study where service users have found health consultations aversive, and felt that some health professionals have not viewed them with respect (see Jonathan in *Listening*) or listened to them or their carers (see Rolf, also in *Listening*).

Since there is a strong causal link between learning disability and mental illness, specifically schizophrenia, autism, attention hyperactivity deficit disorder, as well as between learning disability and epilepsy (Owen, 2012), the current study highlights a concern that people with a dual diagnosis of learning disability and mental health disorder or epilepsy may find themselves marginalised within both specialist services and within their general health services. Those participants in the current study who worked with a health facilitator were helped in gaining the healthcare they needed, but one participant

(Matt) who relied on his father for support felt frustrated that his healthcare needs were not being met or even taken seriously. The finding that some participants felt they had not always been treated respectfully suggests that the attitudes of some health professionals, perhaps especially GPs, towards people with learning disabilities may be affected by their historical association with psychiatric services, combined with the higher incidence of psychiatric, as well as physical, illness in people with learning disabilities. The effects of perceived stigma on the willingness of the person with a learning disability and possibly their companion, to negotiate a more creditable view of the self within the encounter lead to disengagement from the consultation process. In turn, this reinforces their passive role within health consultations, leading to less satisfying and less effective encounters. Only a valuing, non-judgemental approach by the health professional, that allows a respectful relationship to develop over time, can address these barriers in order to promote the self-efficacy of the person with learning disabilities with regard to their health.

### **Overview of Communication Barriers**

This theme clearly shows that many participants did not understand the health problems they were experiencing, what caused them and what their future health expectations might be. Lifestyle advice, while important for improving health outcomes, was sometimes given in a rule-based and aversive way, leaving participants upset and confused and with little sense of control or self-efficacy

Consultations, including health checks, need to be set in the context of being known by the health professional and having health facilitator support to ensure that concerns can be prioritised and service users still have their needs met. Anxiety related to health consultations or some aspect of healthcare was very common, due to: previous negative experiences; a lack of understanding and preparation beforehand to address it; hypersensitivity associated with autism; embarrassment related to undressing, intimacy and embarrassing problems; and fear of test results. Several strategies were adopted to overcome anxiety, but habituation with the person, place and procedure, accompanied by a calm, quiet atmosphere and with the development of a trusting relationship were generally successful approaches.

Some service users, notably those with epilepsy or psychiatric disorders, but possibly also women, seem to have experienced felt stigma. Given that psychiatry is a marginalised speciality within healthcare, this could result in the experience of

consultations being embarrassing and unsatisfactory – there were suggestions that several of the participants who had epilepsy did not like discussing it, and one participant was reluctant to discuss his previous psychiatric care. Overall, the theme highlights the way in which people with learning disabilities are uniquely vulnerable to “discredited definitions of self” (Charmaz, 1983, p170) leading to the burden of fearing disclosure (Scambler & Hopkins, 1986) and formal legitimising of their deficits (Goffman, 1963). To engage in the health consultation means accepting that discredited self; to reject being discredited risks confrontation with a person of higher status. Consequently, some participants either withdraw from engaging in the encounter, or avoid disclosing those attributes they fear may result in them becoming discredited. Past experiences were significantly important to participants in how they made sense of the consultation experience, so having felt discredited in the past led to fear of disclosure and withdrawal from the encounter. This may, at least partially, explain why, despite increased attention to the health needs of people with learning disabilities following a number of reports (Department of Health, 2001; Disability Rights Commission, 2006; Mencap, 2004, 2007; Michael & Richardson, 2008) and the introduction of annual health checks for people with learning disabilities, health care is not optimal (Learning Disabilities Observatory et al., 2012). Consequently, the notion of the discredited self from past health consultations leading to a need to present the self as credible and prevent disclosure of possible discrediting attributes in future health encounters is an important barrier to communication that could result in less effective healthcare.

## Chapter 6: Towards a Comprehensive Explanatory Model of Health Consultations – Past Experiences and Current Perceptions of Health Encounters

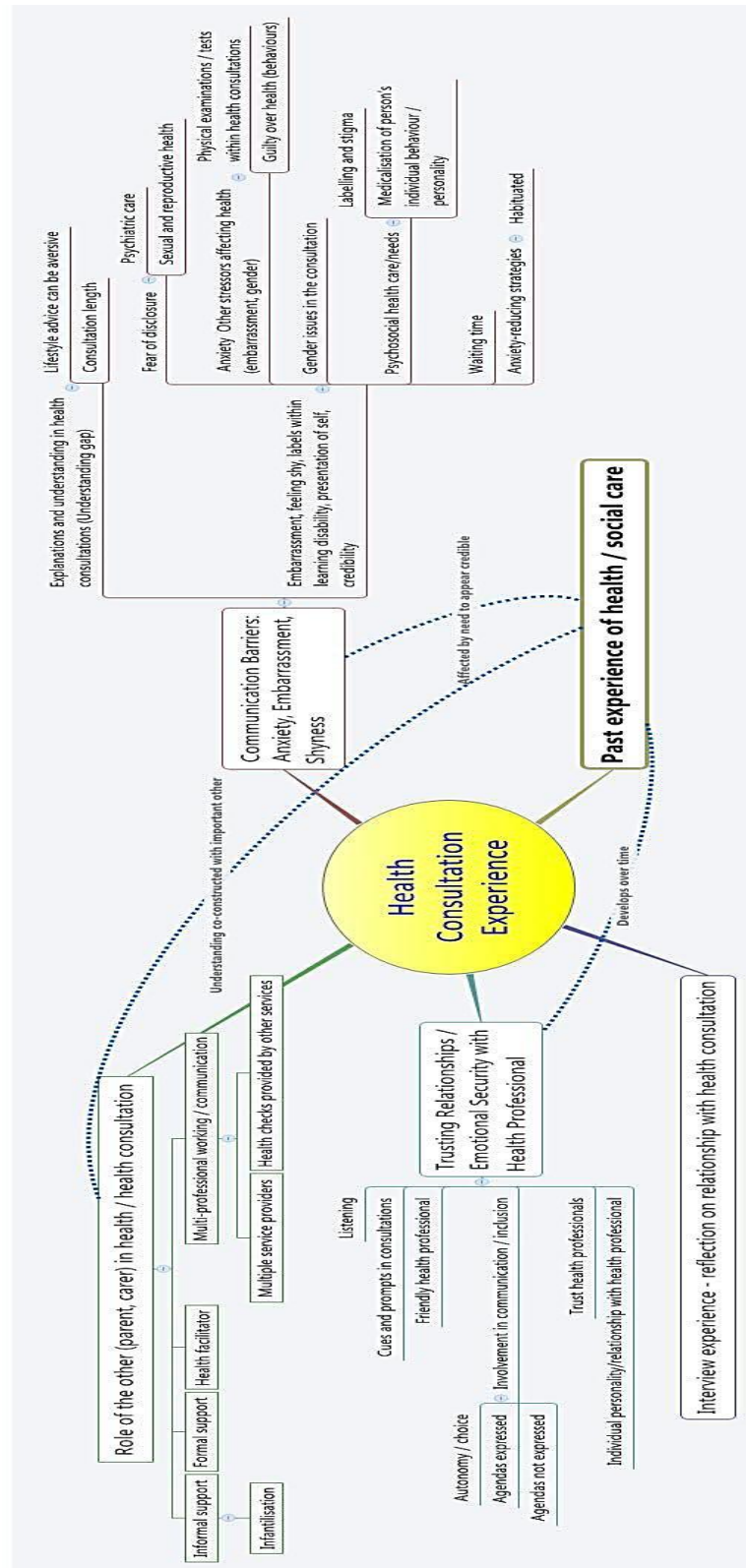


Figure 4 : Overall relationship between themes in health consultation experience for a person with learning disabilities

While the relationship between many of the categories was reasonably clear following analysis and member check, the way in which each of the themes was related to the others required careful consideration of the pathways by which they occurred. The first theme, about the relationship with the professional, was ubiquitous throughout the data, and included the ability of the service user to be involved in the consultation, with the feeling of being known and understood within a long-term relationship with the health professional providing the necessary conditions for expressing agendas and being able to trust them. Previous research having focused on single consultations, this suggested a model for understanding perceptions of consultations that takes into account past experiences of health and social care. Thus, the final analysis had to include the influence of past experiences of health consultations, which had a significant impact on self-concept, engagement with and expectations from health consultations. Another theme, relating to the common need for support by a carer, relative, advocate or health facilitator in health consultations, was the role of the other in relation to presenting the self of the service user, promoting their credibility, giving information to the health professional, supporting service user involvement and helping them to make sense of the experience. This triadic relationship has previously been theorised about and discussed in reports (Department of Health, 2001; Michael & Richardson, 2008) but when it was looked for in the literature, it had not been explored in depth (Perry et al., 2013; Wullink et al., 2009). The importance of the length and quality of the relationship with the companion, particularly because of the multiplicity of health professionals encountered, was also key to understanding previous health consultation experiences and expectations for the future. Past reactions of relatives to specific professionals and encounters had made impressions on participants that coloured their perceptions of health consultations, and the role of the health facilitator in supporting participants and health professionals was shown to be positive for participants. The co-construction of the health consultation by service user carers was significant in their engagement with future health consultations, highlighting the importance of health professionals valuing and engaging with companions, without excluding the service users. This triadic relationship has been promoted in policy documents (Michael, 2012), but is poorly researched and little understood. Its significant effect on the service user experience indicates the importance of addressing it urgently. Communication barriers felt by participants included: the effects of lifestyle advice on self-concept; the perception that there was insufficient time for them to ask questions; anxiety and embarrassment related to examinations; and felt stigma related to disability, psychological concerns, epilepsy, and sexual and reproductive health. Again, even though their current health professional may

have been perfectly supportive and understanding, past experiences seemed to exert considerable restraint even on their ability to disclose their concerns about some aspects of their health. Again, the burden of non-disclosure due to previous experiences of feeling themselves to have been discredited within health encounters or leads to withdrawal from the encounter due to fears of further loss of self. Discussion of the additional barrier of cognitive difficulties affecting communication with the health professional is found in the *Reflections on methodology* chapter, but underpins some of the other issues identified by participants. The data and literature underpinning each of the first three themes are all connected by *Past experiences and current perceptions of health encounters*, which provides a possible model of health consultations for people with learning disabilities. These five overarching themes, and the relationships between them, are represented in Figure 4: *Overall relationship between themes in health consultation experience for a person with learning disabilities*, at the beginning of this chapter.

This thesis, based on the symbolic interactionist viewpoint that our understanding of previous experiences informs our expectations of and conclusions from current and future experiences, has explored the service users' own understanding of their health consultations. In Rachel's boyfriend's words "*It's what's inside that counts*", but several participants left their consultations feeling of little value in the interaction. A few of them, with the support of a health facilitator and a practice nurse who knows them well, have expressed satisfaction with their current care, and have given examples of how this has helped them. However, underlying this apparent satisfaction is the legacy of mistrust that has been left from previous interactions and the suggestion that they find it more difficult to interact with doctors (whether GPs, psychiatrists or other specialists). Another strand from the analysis is that part of the health check is about identifying potential health risks that are amenable to lifestyle change, but several of the participants found this undermined their self-concept, so that they saw themselves as fat or became anxious that their health was at immediate risk. The balance between supporting behaviour change and promoting a feeling of self-efficacy has not been achieved for those service users, possibly because they did not know, or feel known by, the health professional who gave them the advice.

Despite a great deal of research into the health professional-service user relationship and its effects on the consultation, little research seems to have been carried out into service users' past experiences of healthcare and how these have influenced their current involvement in and expectations from consultations. It is known that length of relationship combined with trust are strongly related to trust for the doctor (Roter &



Larson, 2002), and that trust and seeing a regular doctor are important for expressed service user satisfaction with the consultation (Whitfield & Baker, 1992), while the phenomenological study by Frederiksen et al. (2009) suggested this is due to the importance of being recognised as a person by the doctor. People with medically unexplained symptoms have similar experiences to some of those expressed by the participants in the current study, finding doctors reluctant to engage with their world view and explain their symptoms to them (Salmon et al., 1999). There are several factors affecting service user-health professional relationships within the consultation. These include: the importance of authenticity of the health professional's attitudes towards the service user; and the conscientious fulfilment of their clinical role (Salmon et al., 2011). The use of the attachment model (Rogers, 1961) applied to consultations may help to explain why some consultations are more supportive and explanatory than others, looking at both the service user's level of security seeking versus independence, and the health professional's balance between paternalism and promotion of autonomy in the service user (Salmon & Young, 2009). Service users who have a model of the health professional as not knowing or valuing them as a person develop a model of themselves as not worthy of their respect, and therefore build their expectations of future encounters from that perspective. Conversely, the service users who perceive the health professional as knowing and valuing them as a person develop a model of themselves as worthy of respect, and therefore are more likely to perceive future encounters as being respectful, and be more resilient to the occasional miscommunication.

It is clearly shown in the current study that where participants are known by their health professional over a long time, they experience satisfaction with those consultations (see Edmund and Jonathan's relationships with their practice nurse, for example). However, there are also many examples of past experiences making the service user anxious, less willing to engage in the consultation or otherwise unhappy with their healthcare. These have been covered in more detail previously, but by examining them as a group, the importance of the cyclical nature of health encounters, and the way participants think about and use their previous experiences to shape their current perceptions of health consultations (Charon, 2006), suggested the importance of incorporating this factor into any model of health consultations. Indeed, it may well be one important reason why a regression analysis of previously researched factors related to health consultation patient satisfaction only accounted for 33% of the variance (Pawlikowska et al., 2012), as it did not take into account the past experience and expectations of the service users.

At a basic level of recognition, it is necessary for health professionals to communicate with service users, even if the person is unable to respond verbally. However, in several cases, the health professional did not speak to the service user, or even give them eye contact (Rolf, Elaine, Grace). Not only does this prevent them from taking part in the consultation, but it provides a model for their expectations of future consultations. Several service users had experienced unpleasant procedures without prior warning, explanation or preparation, leaving them with feelings of anxiety that coloured the whole consultation for them, making it difficult for them to engage with the process. dEdmund, though

Some participants had experienced a lack of control in the past that had sensitised them to health professionals who were not interested in their problems. For example Jonathan, who had spent several years in a long-stay treatment and assessment unit (*Expressing agendas*) felt he had not been listened to by a doctor, who “*did not want to know*”, and ended up telling the doctor “*where to go*”. His mother had made a complaint about this (*Listening*), but his past experiences had left Jonathan untrusting of doctors, and preferring to see the practice nurse. Owen, who was generally quite imperturbable, felt that his life was controlled by his peripatetic care staff putting him to bed too early (*Multiple service providers*) and was unhappy that his own doctor, who visited him to give him check-ups, did not see him when he had an acute emergency out-of-hours (although an ambulance was sent to take him to hospital), demonstrating how important he found being seen by someone who knows him.

Some participants described experiences where they felt “*told off*”, for example Lindsey felt told off by the doctor for being embarrassed to undress for an examination (*Expressing agendas*). Her interpretation of the event has magnified the embarrassment she already felt and increased her anxiety for future encounters with male doctors, because of the possibility that she may need to undress for an examination. Rachel also does not like seeing male doctors, but Mandy, while expressing the same feeling (*Anxiety, embarrassment and gender related to health encounters*), feels able to request a female doctor for her health checks, the last of which she was happy to attend without her parents (*Informal support*). Rachel also felt “*told off*” by the practice nurse for being fat, and interpreted the warnings of associated cardiac disease to mean that she was going to have a heart attack there and then. This made her cry in the consultation, so her carer had to be telephoned to come to the practice and support her (*Informal support*). This, combined

with her fear of needles, her embarrassment about removing clothes and anxiety around physical examinations (*Anxiety, embarrassment and gender related to health encounters*), means that Rachel experiences a loss of self in health encounters, making it difficult for her to engage in them in a meaningful way. For instance, when she was disappointed because she was not given antibiotics for a “chesty” cold and blocked sinuses, and did not understand why, she did not ask the doctor for an explanation (*Expressing agendas* – Henry had a similar experience). Tony, Owen and Grace also found health advice aversive, effectively feeling the health professional had taken on the parent role within the encounter. This adoption of a passive relationship with the health professional creates barriers in future encounters, even if the health professional uses a person-centred approach, suggesting a model of health consultations in which loss of self in previous consultations creates barriers in future consultations that can only be overcome through the development of a trusting relationship over time.

Similarly, some participants had difficulty in understanding or feeling understood by their doctors, confirming their difficulties in both communicating their needs and having them responded to in a way that did not undermine their sense of self. For example, Lisbet felt bad-tempered because she did not know the person who carried out her health check (*Individual personality/ relationship with health professional*), and Matt found that a practice nurse who did not “understand” him over-reacted to his high blood pressure (*Lifestyle advice can be aversive*). He also felt that his doctor did not take him seriously over his knee and mobility problems, but was unable to trust his doctor and the system sufficiently to ask for a physiotherapy referral. Lindsey has difficulty understanding doctors (*Member check, Explanations and understanding in health consultations*), especially in hospital, partly because of the use of professional language, partly because she has a hearing impairment, but also because she is anxious:

*Lindsey: Advice can make me nervous, scary – can’t tell the doctor how he makes me feel. I could say it to the nurse. It would be better if I could see the doctor with the nurse there. I see the nurse more than the doctor, because I prefer the nurse. She’s clear, and she understands what I’m saying to her.*

Participants need to feel valued and listened to, and known by the health professional, in order to develop a trusting relationship, the essential requirement for expressing needs and asking questions, both of which are key to a concordant consultation.

Daniel felt that he could not ask questions of the doctor because he was too shy and there was not enough time (*Formal support*). Time is a scarce commodity throughout

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health services, and may limit the interaction between health professionals and service users (Chan, Jones, & Wong, 2013). However, perception of time available by the service user is related to a feeling of being heard, rather than actual time taken in health encounters (Ogden et al., 2004). This perception that the health professional does not have the time to explain test results, diagnoses and prognoses, procedures, interventions and advice in a way that can be understood by the service user, reinforces a view of the self as not being worthy of extra time, and may be exacerbated by interactions with health professionals who do not already have a relationship with the service user and understand their communication needs.

Lindsey and Edmund both think doctors are more important than nurses (*Member check*), and possibly, therefore, less approachable, but this means that it is more difficult for them to ask questions of the doctor than the nurse, and yet they also believe that doctors know more. This hierarchical model of communication positions them below the health professionals in their value, with a consequent effect on self-esteem that, again, cannot be overcome in the space of single consultation, as found in *Trusting relationships and emotional security with the health professional in the consultation experience*. Catherine (*Expressing agendas*) and Grace (*Involvement in consultations*) also feel that the nurse understands them better, possibly because they are seen by the same nurse each time, and possibly because nurses are not as high above them in the hierarchy of healthcare, but the use of nurse practitioners to carry out health checks for people with learning disabilities could be seen as a second-tier service, or a barrier to seeing a doctor, and may reinforce a view of being a less valued user of healthcare. It also means that, when a service user does see a doctor, they do not have an existing relationship, which can lead to reduced engagement and poor communication within the consultation. This is further exacerbated by a lack of continuity across multiple services due to more complex health needs (*Multiple service providers*).

This study also identified that the frequent need for a third person in the health consultation created an added layer of complexity that potentially reduced the engagement of the service user in the consultation, not because the carer (especially if it was a relative) wanted to exclude them, but because the health professional communicated with the carer in order to gain important information about the health status and needs of the service user, and because sometimes their need to gather information made it difficult for the service user to engage in the consultation. Sometimes, the carer would not represent the service user's anxieties, in order to present a credible picture to the health professional and

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develop a working relationship with them, but this further disempowered the service user within the consultation. Relatives, particularly, tried to promote the personhood of the service user, but needed to present themselves as credible sources of information about their needs in order to earn the respect of the health professional and thereby achieve optimum care for the service user. This balance between promotion of personhood and presentation of credibility was made more difficult where the health professional was not well known to them, suggesting a further reason why multiple service providers could provide less effective consultations, even if they are well-meaning. However, Catherine and others found the health facilitator helped with the communication with different providers, as they are credible and known to health professionals and role-model positive engagement with service users.

This hierarchical relationship and the importance of presenting a credible self can create a strong sense of embarrassment or inhibition, particularly in relation to use of language, or issues related to sexual and reproductive health. For example, James found the health professional's use of words such as "*boobs*" or "*balls*" in the health consultation embarrassing (*Expressing agendas*), and several of the female service users had negative experiences of examinations or smear tests, and felt embarrassed when being examined by male doctors. If their companion in the consultation chooses not to present their concerns, the service user is effectively silenced. For example, Ann felt that the nurse who carries out her annual health checks could not understand her, so she was unable to ask about why her epilepsy is getting worse, particularly as she is accompanied by different carers and they had not kept records of her seizures (*Expressing agendas; Psychosocial healthcare/needs/labelling and stigma; Formal support*). Mark's mother did not express his fears about his headaches being caused by "*something on the brain*", possibly to maintain his credibility, but this left Mark with unresolved anxiety (*Expressing agendas*). Most service users found needles were sources of anxiety, and many of them required regular blood tests and sometimes injections, again creating a barrier to an equal relationship.

It is important to note that not all past experiences are negative, and that negative experiences are more likely to be remembered and related than positive ones, but they are a useful reminder of the importance of understanding the perspective and experiences of the person in the consultation. This is particularly important when previous feelings of being discredited within the consultation, leading to a need to present themselves as credible, may lead to withdrawal from the consultation. In the study by Ali et al. (2013), accessing health service was complex, time-limited and stressful for carers, meaning that

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service users were not always taken to appointments; complaints about poor care were made with little result, but sometimes poor care was not complained about as it might affect future care. A lack of continuity of care was also identified as part of a range of negative health experiences, some of which were quite shocking. A further theme was that of staff having patronising attitudes and insufficient knowledge of the health needs of people with learning disabilities. Some examples of good practice were given, but the overall picture is one of poor healthcare from hospitals and GP practices (Ali et al., 2013). In the current study, even when participants expressed satisfaction with their healthcare consultations, further conversation often revealed anxiety or mistrust of health professionals based on prior experiences, or an acceptance that their carer managed their health for them (see *Involvement in communication/inclusion; Individual personality/relationship with health professional; Anxiety, embarrassment and gender; Informal support; Member check*). This emphasises the importance of continuity and regular consultations to build trusting relationships that can overcome these barriers to healthcare.

The current service requirement that annual health checks, generally carried out by a nurse practitioner, with additional adjustments in the form of a health facilitator, easy-read leaflets, longer appointments and appointments at quiet times may be an improvement on previous provision, but by themselves are not sufficient to overcome the barriers that people with learning disabilities meet when trying to access appropriate healthcare. Previous experiences of stigma, and current marginalisation within mainstream general practices, mean that people with learning disabilities may still perceive themselves to be less valued within mainstream services, and still fear engagement with health professionals, which, even in a person-centred consultation where the health professional achieves high standards of care and communication, will reduce its effectiveness.

The overall relationship between the findings from this research and the existing literature will be explored in chapter eight *Setting the findings in the context of the literature – implications for future research*. The implications of this model of health consultations for people with learning disabilities on service planning, provision and practice will be discussed in chapter nine *Implications for practice*.

The next chapter, *Reflections on methodology*, will explore the quality of the research methodology used to develop this model, and identify its strengths and limitations to establish its credibility, originality, resonance and usefulness (Charmaz, 2006).



## ***Chapter 7: Reflections on Methodology***

### **Introduction**

The first part of this chapter will evaluate some of the methodological issues raised in this study, identifying how they were managed and how future research might improve on this study. The modified methodological approach and barriers to research into healthcare for people with learning disabilities has already been discussed in the *Methodology* chapter, particularly in *Study design* and in *Ethical issues revisited, real world research and study modifications*, as well as in *Involvement in communication/inclusion*, but the question of learning disabilities empowerment in research will be considered. Then I will reflect on my experiences of interviewing participants and the parallel insights they gave me into health consultations. The second part of the chapter assesses the implications of the feedback from the member check session (Charmaz, 2006). Finally, the research and its findings will be evaluated overall, particularly in relation to the credibility, originality, resonance and usefulness of the analysis, evaluating the strengths and limitations of the research.

### **Evaluation of the Research Process**

The first family I interviewed, through a health consultation, provided insight into the difference between interviewing in clinical and home environments, with implications for the health consultation process. The focus groups immersed me in a small part of the closed world of the participants, where I was a stranger, so their speech, other forms of communication and the context of what they said was not always easy to understand. However, they were patient, partly because this subject was so important to them, and partly because they wanted to help anyone who was interested in them as people. Then, carers talked about this research to other service users who wanted to be involved, and finally, when I needed to follow-up on themes to complete my analysis, a chance contact with a health facilitator allowed me to talk to five more people about their health consultation experiences. Throughout the process, months were spent seeking ethical approval and gatekeeper access for each part of the study, and overcoming the recruitment difficulties involved in this study. These and other barriers to answering the research question will be discussed below.



### ***Research Barriers and the Research Process***

The procedural, ethical and professional barriers to carrying out this research (see *Ethical issues* in Chapter 2), may explain why qualitative research seeking service user views about the health experiences of people with learning disabilities is not very common (Nocon, Sayce, & Nadirshaw, 2008), although becoming more so (Ali et al., 2013; Brown et al., 2012; Castles et al., 2012; Gates, 2011b; McCarthy, 2009; Michell, 2012; Murphy, 2012; Perry et al., 2013; V. Turk et al., 2012). The Government White Paper *Valuing People* (Department of Health, 2001) formalised access to mainstream primary health services for people with learning disabilities, and a rights-based emphasis on equity of access to them. A number of reports highlighting health inequalities and care quality issues in health provision for people with learning disabilities have led to the introduction of a learning disabilities observatory to gather data on and research healthcare for people with learning disabilities, and a specific service where GPs are paid to provide annual health checks (Disability Rights Commission, 2006; Improving Health and Lives: Learning Disabilities Observatory et al., 2012; Mencap, 2004, 2007; Michael & Richardson, 2008). This has led to an expectation that services should be evaluated to ensure that they meet the needs of service users, but much of the evaluation is either based on outcome measures, such as the number of referrals from health checks, or on generic patient satisfaction surveys, from which service users may be excluded. The recent studies that have been carried out generally access service users through large stakeholder studies (Gates, 2011b; Perry et al., 2013; V. Turk et al., 2012), or through audits by learning disability professionals (Brown et al., 2012; Castles et al., 2012; Murphy, 2012), through community meeting places such as day services centres (Ali et al., 2013), through recruitment by health professionals (McCarthy, 2009), or through existing groups such as self-advocacy groups (Michell, 2012).

Lennox (2005) has already identified that barriers to access, partly for ethical and safeguarding reasons, make recruitment to large-scale health evaluation studies difficult, and since I was using a grounded theory approach for data collection and analysis, I was aiming for at least twenty participants. Charmaz advises that it is the ability of the data to answer the questions posed that matter, so the data collection strategy should be focused, but she also advises against “skimpy data” (Charmaz, 2006, p. 18). I sought ethical permission to interview 25 participants, in case I needed extra interviews to extend my theoretical sample. Although I prepared and allowed time for ethical barriers, the constraint on recruitment was mainly the need to gain access to participants via another organisation. Effectively, health organisations had little or no motivation to take part in my

research – as well as using time and resources, it could identify failings, and I was an outsider researcher, dependent on them for access. Consequently, the only way I could gain access to a sufficient number of service users was via social services and the independent advocacy service, who were also interested in evaluating the health services that service users received. Barriers also exist in terms of trust – service users are generally aware that outsiders are potentially harmful, so unless you are introduced to them as trustworthy by a trusted family member, friend, health professional or carer, they are unlikely to want to participate (Lennox, 2005). The support of the relatives' group and the advocate was essential for this. However, one health facilitator who worked closely with a GP practice helped me to contact five further participants, who were either female or had psychiatric disorders or both.

Having built these links with practice, future research in this area would be easier to accomplish, but it is clear that health services and individual gatekeepers at all levels can make research difficult to carry out, even when ethical and Trust research and development approval has been given. The Francis Inquiry (2013) has urged more research into compassionate and respectful care in the health service, and it is likely that the environment is more amenable to research now. While insider research by people who work in the health service is less disruptive and more naturalistic, as well as making it easier to access service users and health professionals (Bonner & Tolhurst, 2002), it can be difficult for service providers to evaluate experiences openly. In the current study, key gatekeeper access to GP practice consultations was almost impossible to obtain, but day services, advocacy services and health facilitators all gave access to support health service evaluation for people with learning disabilities. The independent role of the researcher as an academic, rather than a health services employee, means that the analysis is completely focused on the viewpoint of the service user. This makes the findings more robust than insider research alone, although access to service users was still partially via service providers and data saturation in the area of anxiety, embarrassment and stigma was only partially achieved.

### ***The Interview Experience – Personal Development, Barriers and Insights***

#### **Communication in Interviews**

I identified, in my own communication in interviews, some of the pitfalls awaiting the health professional who is not ready for them. Early in the interview process (Interview 1), the speed at which I spoke and asked questions was sometimes too fast, and I occasionally asked one question before the service user had finished answering the previous question. I identified that this was happening from listening to the audio-recordings and made a conscious effort to slow down and listen more carefully. I also started gathering data related to the code of the interview experience, as I could see parallels between that and the consultation experience. Despite being an experienced learning disability nurse, my lack of recent practice had impaired my communication skills, serving as a reminder that health professionals could benefit from simple experience with people with learning disabilities and training sessions to remind them of some basic considerations, such as reduced cognitive processing speed making conversation slower (Mee, 2012). Additionally, that interview was the one held prior to a health consultation, so it was in a GP practice and time-limited, again pointing to the effects of time and place in limiting listening behaviours and the parallels with practice. At times, I also found it difficult to explain what tests or internal parts of the body were to participants, even with help from people who knew them, resorting to drawing diagrams, as I did not have “easy-read” leaflets (Interview 12). In the same interview, I found the participant had great difficulty in understanding what I was trying to ask about, so I ended up asking quite closed questions in order to get an answer. However, yes or no answers are not satisfactory, as they do not give any idea of understanding or veracity, as the person might just give the answer they think is wanted (Gudjonsson & Clare, 1995). Sometimes, when trying to check a participant’s understanding in this situation, it could sound rather interrogatory, which could pose problems of information-gathering in a health consultation, making an informed companion beneficial to the process. This was highlighted when I asked a question that one participant could not answer, but her companion was able to provide relevant information and prompt her to a related response (Interview 14). Sometimes, I did not check someone’s understanding of, say, medication, in order to avoid making them feel bad. I also found that medical language could be confusing. I asked one person about breast self-examination, and she asked me if I meant breast screening, and it transpired that she thought I meant mammograms. Checking meanings and using precise language were important in the interviews, suggesting they are also important in consultations.

After one interview, with a participant and parent, the parent expressed strong views about sexual behaviour, so I found myself very much in a child-to-parent role, similar

to that of the participant (Berne, 1961). I was not prepared for this, and did not feel that it was my role, as a researcher, to get involved in a discussion about it. However, this did raise the issue of privacy to discuss sexual and reproductive health in the health consultation in the presence of family members, and made me aware, again, of the difficulty health providers might have in managing triadic consultations where service users need the support of a companion but might also need some privacy. I also found that participants would have something that they wanted to talk about and that, even if I did not perceive its relevance initially, it was helpful to listen because sometimes it would reach a related point, and also it allowed the person to express their concerns and feel valued in the conversation. Once they had expressed this, it was then easier to change the course of the discussion. This does take time though, and is another reason why consultations for people with learning disabilities need time, and also why feeling secure with a known health professional can be more effective and time-efficient.

Again mirroring issues that were constructed from the data analysis, I sometimes found the re-framing of my questions or interjections of the companion posed difficulties in the interview. Some of these issues were unlikely to be replicated in a health consultation, for instance one such incident was with the participant's bus driver, who was waiting to take him home and trying to make him answer more quickly, but sometimes, when I was happy to give the participant time to think before they responded, a paid carer might answer on their behalf. Silence can feel embarrassing, but I found that, when I was able to use it, service users were often willing to make the effort to respond thoughtfully to questions. Sometimes, the carer was interjecting in order to provide context, probably an extension of their support in helping the participant and researcher to build a relationship, and I accepted these interjections, which generally reduced as companions gained confidence in my ability to communicate with the participant. Both Mark and Rolf, despite having communication difficulties, enjoyed being interviewed and worked hard to express their thoughts. This showed me that inclusion and involvement in quite abstract conversation is possible with patience, time and encouragement. Unfortunately, ensuring consent was informed took a long time, and this not only caused a problem with the pre-consultation interview, but also made companions impatient sometimes. Informed medical consent is a serious issue for people with learning disabilities (Luke, Redley, Clare, & Holland, 2008), and I had prepared "easy-read" leaflets explaining the research for service users (King, 2011). However, due to the ethical requirements for this document, it was necessarily long, and it took about ten minutes to obtain consent from participants,

suggesting the importance of acute hospital liaison nurses to assist with seeking informed consent.

I frequently found that the openness of the situations in which people with learning disabilities spend their time was detrimental to building up a relationship – service users and carers would walk in, often without knocking, possibly to ensure the well-being of the service user, and I wanted to make the process as transparent as possible so that people did not have concerns about the participants' experience, but it made continuity of conversation and the ability for the service user to disclose sensitive information difficult. I believe this would be less of a concern in a health consultation.

Other issues that can affect the quality of the data are data collection tools – in one focus group meeting, I lost about twenty minutes of data because a service user accidentally pulled the cable out of the recorder with his chair, and I did not notice the red light had gone out. The data was lost because I was too busy co-ordinating the focus group to take notes as well (which would also have been a barrier to the interaction). However, after that, I made sure to check the recording light regularly and take a spare recorder with me in case of equipment failure. In the member check meeting (see *Member check*), where small groups discussed the findings from the study, we met in one large room and spread out, but the nature of the recorders meant that voices from other groups were picked up and it was sometimes difficult to hear the speaker clearly. Some of the service users had quite severe speech impediments. This meant that not only did they have to repeat what they said, but sometimes I was unable to understand them. Occasionally, I would miss what they said in the interview, but be able to hear it by slowing down the audio-recording afterwards. This made me realise just how patient many of the service users were with my unsatisfactory attempts to understand them (see *Member check* for more discussion). I also found transcribing the recordings exceptionally slow for the same reason – it took me up to 12 hours to transcribe an hour of interview. This was partly because I transcribed them verbatim, including pauses, and the use of utterances such as erm, aah, and hmm, so that the quality of the interaction had depth and gave some impression of the impact that learning disabilities could have on communication (Robson, 2011). This was not possible with the data from the member check meetings, due to the poorer quality of the recordings, but I wrote detailed notes from the recordings instead. Overall, focus groups were useful for identifying areas of interest and helping participants to feel at ease, but paired or one-to-one interviews were more helpful for discussing sensitive issues.

Sometimes, I would ask a question and the participant would dissemble, leaving me unsure whether they had difficulty in formulating an answer, or if they did not want to answer that question. Certain questions, such as asking if there was anything they thought could have been done better, were difficult for people to answer, so I wrote a memo about Fear of Disclosure.

### **Fear of Disclosure**

On several occasions during data collection, there were signs that participants were fearful of disclosing dissatisfaction with their healthcare (memo 12). One carer, whose relative had been recruited via the GP practice, was anxious to express satisfaction. In one focus group, Lisbet said that she did not ask the doctor any questions, she did not want to ask any, she did not know the health professional or know whether they were a nurse or a doctor, and she felt “*bad tempered*” when she went for her health check, but could not explain why. Shortly afterwards, she left the group abruptly and, after one of the social carers went to find out why, it transpired that she was worried about getting people into trouble if she said what she really thought, but that she still wanted to take part. Jonathan identified that, although the practice nurse generally understood how he felt, the doctors sometimes did not:

*H: And if they don't understand how you feel, what mistakes do they make?*  
*Jonathan: Oh they make the mistake not me. That's their doings innit?*  
*H: Mm. What do they do?*  
*Jonathan: No, I'm not to say.*

but was reluctant to discuss his dissatisfaction. Another service user asked the driver not to tell the carers about the interview, possibly thinking it was about care at home, but when it was explained that it was just about doctors and nurses, the person was reassured.

Similarly, Grace made a comment that:

*I see the nurse. I don't go to the Dr, he's rude. He does, he talks to your foot...*

but later telephoned me because she was very worried that I would be telling her doctor what she had said to me in the interview. One of the other service users had told her that I was telling their doctors what they had said, and she had been worried all weekend. I thanked her very much for telephoning me and reiterated that I did not tell anyone, but particularly not her doctor, what she had said, and that the report I wrote up would not have anyone's names in it. It took about half-an-hour to reassure her, but she seemed to be

happy that I was not doing anything she did not want and agreed that she still wanted her interview to be part of the research. She later discussed it with her advocate, who reassured her that she would not have allowed me to interview her if she did not think I was trustworthy. However, there were implications for the integrity of the study, because some service users were unwilling to either take part in the study or disclose sensitive information because they had been told that what they said would not be kept confidential. This is a clear disadvantage of being an outsider researcher, but it is possible that participants would self-censor with insider researchers as well. It reinforces the importance of people with learning disabilities knowing someone well enough to trust them (see chapter three *The role of trusting relationships in effective communication*).

### **Member Check**

A member check, to check the veracity of the analysis, was carried out in October 2013. Invitations were sent out to all the participants, and seven of the original participants attended, accompanied by a health facilitator, a carer, a social services manager and the mother of one of the participants. The overall analysis was presented to the whole group, then they were divided into three small groups with their supporters, and each group was asked questions about their views on each major theme from the analysis. The facilitator of each small group was a senior academic with learning disabilities qualification. The group discussions were recorded and the findings outlined (see Appendix 10). The people who attended the member check almost universally supported the analysis and were able to add depth to the data. For example, they were able to empathise with the embarrassment of a health professional who was reluctant to ask them to repeat themselves, and made assumptions about what they meant, but felt that it was important that what they actually wanted to say was heard, even if it took more time and effort. The member check suggests that, even though this is a constructed analysis, it is based in the reality of the participants and represents it back to them in a way that they understand and identify with.

### **Strengths and Limitations of this Research in Relation to Constructivist Grounded Theory**

Throughout this thesis, I have attempted to identify where practical circumstances and, initially, the use of a study from a different methodological perspective, have led to weaknesses in the data collection and analysis. I have learned from these how to improve my own research skills in the future, they have not had a significant effect on the findings.

Indeed, in some ways the initial misconception of the study meant that I explored another approach in depth and identified the strengths of the current approach. I also gained more insight into the consultation experience, so as field work it was not wasted. This gave me more confidence when I was interviewing service users, as I had some understanding of the context of their conversation. The slow processes of ethical permission, access and transcription also had unforeseen benefits – mainly in deepening my understanding of the ethical and practice issues, and helping me to understand the various structural elements of the healthcare system, which seem rather complicated even to me, and must seem Byzantine to service users and their carers if they attempt to understand it. The transcription process required deep immersion in the data, and enabled me, when I met up with service users after months apart, to still enter into their world, because I felt that I knew them so well. Having built relationships with both service users and service providers, and linked to a naturally existing self-advocacy group, it would now be possible to consider service user-led research, which would not have been feasible at the start of this study. In order to critique this thesis in depth, I will use the criteria for grounded theory studies developed by Charmaz (2006).

### ***Credibility***

The data and the analysis show detailed understanding of the health consultation experiences of people with learning disabilities, through a structured analysis grounded in the data, and its relation to the literature of health inequalities, current policies and services, and the importance of health professional/service user relationships in promoting an experience that positively affects both the psychological and health outcomes for people with learning disabilities. A total of twenty-five people with learning disabilities were interviewed about their health consultation experiences, some more than once, using a combination of pre-existing group interviews; interviews in pairs and single interviews; a health check consultation was analysed; and background information was obtained by discussing the study with parents of service users, health managers, health facilitators and a GP, and informally interviewing a practice nurse and a health facilitator (although this was not recorded verbatim, for ethical reasons). Theoretical sampling was used to test the categories developed in the early analysis, attempting to achieve data saturation in those areas where the data were insufficient, that is psychosocial health needs, embarrassment, anxiety, gender, labelling and stigma. The participants varied widely in their cognitive and expressive communication skills, gender, age, health needs and living situation, and were interviewed in a wide variety of settings, from GP practice, to home, to day centres.



Interviews were carried out with individuals, pairs of service users and larger groups.. The observations were as deep as possible, given the variation in communication skills, and by comparison with the generic thematic analyses used in similar studies, which mostly covered a greater breadth of health experiences in a more pragmatic way (Brown et al., 2012; Gates, 2011b; Perry et al., 2013), the current study accessed the emotional and social processes underlying the health consultation in more depth.

. Despite memo writing (see Table 17: *Memo subjects*), prompting future theoretical sampling to achieve data saturationthe limits of time and recruitment, the sensitivity of some of the themes raised, and the limits of verbal communication meant that some themes are still only partially explored. For example gender, sexual and reproductive health, and experiences of stigma and labelling provide some evidence of barriers to communication, but need further research to capture their full meaning.

Table 17: Memo subjects	
Self-efficacy and anxiety	Understanding gap
Labelling, stigma, learning disabilities and epilepsy	Psychiatric care
Health checks – psychosocial assessment	Individual personality
Cues and prompts the body – ownership/control	Lifestyle advice can be aversive
Role of the parent/carer	Lay explanations
Sexual health	Training need
Helpful approaches in the consultation	Service provider expectations
Self-concept	Motivation for health behaviours
Gender and the body	Specific disability needs/effects
Influences on the health check experience	Coding self-efficacy
Methodological issues	Towards a core category
Fear of disclosure	Embarrassment
Health outcomes	Authenticity
Anxiety related to healthcare	

The analysis has aimed to explore the meanings of health consultation experiences for the participants, and how those meanings affect their ability to engage fully with them and with their own healthcare. This needed a lot of raw data, and some conversations that were complex and sometimes difficult for participants, but the context of the conversation and the quotations throughout this thesis have been used to demonstrate the strong relationship between the data and the findings. However, I have also identified my professional and philosophical standpoint clearly in the context of this thesis, and used reflections, memos and field notes to identify where these had a clear effect on my methodological decisions, data analysis and conclusions. These also enabled me, with the

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aid of my supervisors, to identify where some codes, although grounded in the data, had been related to a theoretical construct too soon (such as self-efficacy, which became loss of control/self-efficacy to show that self-efficacy was just one theoretical perspective on the phenomenon), and to follow the codes that hinted at the meaning of the experience, not only the procedural events and outcomes of the consultation. Without this focus on meaning, and its effect on the self, based on a symbolic interactionist approach, the analysis would have focused on the single encounter, and its behavioural or intervention outcomes, and would not therefore have produced a cyclical model of health consultations. In addition, from the brief relationships I developed with participants I was able to understand a great deal of context and historical care experiences, due to having practised as learning disabilities nurse (mostly with service users who challenged the service). This was particularly important for understanding how difficult it was for many participants to express their views, particularly if they had lived for any time in learning disabilities or mental health unit, which made the fear of disclosure clearer in the analysis. This highlighted the importance of anxiety, embarrassment and stigma and their role in the overall possible model.

***Following Charmaz (2006), I did not use axial coding, but I reorganised my coded data until I was left with a structure of codes and their relationship that fitted the data (see Overview of data analysis). Once this was achieved, I analysed the data from each theme, comparing it with relevant literature from learning disability nursing, health psychology and health encounter research, to build a more complex model of the findings and the processes constructed from the data. An overview of the relationship between the model and the literature will be discussed in Setting the findings in the context of the literature – Implications for future research. The logic of the analysis suggests that secure relationships are essential in effective health consultations for people with learning disabilities; that these are made more difficult by complexity of need, multiple service providers and the need for support within the consultation, but this can be helped by having a dedicated health facilitator and acute liaison nurse. Additional barriers to building relationships and communicating in the health consultation exist for people with learning disabilities due to inadequate explanations and understanding, feelings of being hurried, embarrassment, previous experiences of stigma and negative experiences that can make the effort to appear credible within the consultation, and so have concerns addressed, quite burdensome. Underpinning all of these difficulties is the loss of self within the health consultation due to an accumulation of previous experiences of exclusion and felt stigma, due to having learning disabilities, which inhibit engagement with the process through a lack of trust in the health professional. The model developed (see chapter six Towards a comprehensive explanatory model of health consultations) is grounded in the data, which is given, in context, to illustrate and support the constructed themes. Originality***

The handful of original research articles that have analysed the health consultation experience for people with learning disabilities have generally used a pragmatic, thematic analysis, which has produced insight into many aspects of the experience. However, this thesis has focused on the meanings of the health consultation experience for the service user, and shown how those consultations are different or similar to other health consultations so that, not only can learning disability health consultations be informed by findings from other fields of health, medicine and social care, but some of the findings from this thesis can be applied to the wider literature and practice of health consultations. This thesis places health consultations for people with learning disabilities into the health psychology and psychoneuroimmunology literature, showing how previous negative experiences can increase the stress of health consultations and interventions for people with learning disabilities, leading to poorer health outcomes that maintain health inequalities. Consequently, it shows that annual health checks, without a person-centred approach within long-term trusting relationships, are not in themselves reasonable adjustments. This is a new model of health consultations for people with learning

disabilities within the literature. It demonstrates the primary importance of knowing and being known by the health professional over time, to facilitate a secure relationship in which communication can be more successful and better psychological and health outcomes can be achieved. This has not been definitively demonstrated as a key finding in learning disability research before, and although identified as a common finding in health consultation research (Ridd et al., 2009) has not been explored in any depth in the general health psychology literature. Indeed, little research has been carried out in the last ten years that features the longitudinal nature of relationships in the analysis of effective health professional-service user consultations.

Many learning disability research papers and reports identify weaknesses in healthcare and give examples of grossly stigmatising behaviours and care management decisions. This paper has shown that, while most health professionals in the current service are not overtly stigmatising, past experiences, felt stigma and feelings of embarrassment, anxiety and fear of disclosure are limiting the ability of service users to engage with and gain the full benefits available from health consultations. Service users and their carers find qualified learning disability nurses helpful in aiding communication with other health professionals, co-ordinating care, advocating on their behalf, ensuring they understand and can consent to interventions, and in relieving the stress of negotiating their care needs, and where health facilitators are involved in GP training, this can improve the health consultation experience for people with learning disabilities. This finding has been suggested in previous studies (Gates, 2011b), but the current study adds depth and meaning to the finding, as it identifies not only the extra communication skills and sensitivity to the needs of people with learning disabilities, but also the importance of the long-standing relationship and knowing the person that make the health facilitator in the current study so effective for service users. There is also an interesting possibility that possessing a dual qualification (learning disability and adult nursing) may add value to the role.

### ***Resonance***

In terms of category development, it is difficult to know if data saturation is ever achieved or achievable, but the discussion at the member check meeting (see *Member check*) suggested that the themes generated accorded with the views of service users, and that they could give examples from their own experiences that supported the findings. For example, they talked about their previous experiences in hospital and primary care that

affected how they felt about going to see the nurse or doctor, and they identified the importance of being valued as a person. It is clear from *The data analysis process* in chapter two that the generation of codes, the iterative nature of the analysis and the construction of themes consistently underpinned the goal of achieving depth and accuracy in the analysis. Throughout the detailed analysis in the thematic chapters, the findings have been presented and structured based on their context and meanings within the data, and related to relevant bodies of literature. Not surprisingly, similar themes have been found in the learning disability literature. However, these have not focused on the meaning of the health professional-service user relationship, its effects on the person's self-concept within the consultations, and its relationship with health outcomes. Similar themes have also been found in the health psychology/ health consultation literature, although they do not seem to have been followed-up in terms of recent research, and this is the first study that has attempted to relate learning disability health consultations to the general health psychology literature in any depth. The importance of the triadic relationship within the health consultation for people with learning disabilities has not been explored in any depth before, and is worthy of further research. Overall, the study accords with findings in the general health psychology literature, suggesting that people with learning disabilities want the same good communication with their health professional as other people, based on a long-term relationship with a health professional who values them as a person, believes what they say, and whom they trust to be genuine and acting in their best interests. Thus, the study has resonance both in terms of the member check and of relevant literature in related fields. It also has explanatory power in identifying a possible unknown factor: prior perceptions and expectations of health consultations, based on past experiences. This may explain the inability of regression analyses of discrete factors within the consultation to explain satisfaction with health consultations (Pawlikowska et al., 2012; Peltenburg et al., 2004).

### ***Usefulness***

The discussion of how this analysis adds to what is already known about health consultations in general and those for learning disability in particular can be found in *Setting the findings in the context of the literature – Implications for future research*, but it clearly has utility in providing a model of the health consultation for the person with learning disabilities, which takes into account the effects of their past experiences on their current expectations and engagement with health professionals in health consultations. This model can be used to suggest new directions for research and new ways of evaluating

practice, and provides connections by which areas of research in other disciplines can be used to develop new understandings. There are clear links to individual practice to address the issues of relationship-building, with particular attention to the relationship development affected by complexity of care, triadic consultations, anxiety, embarrassment and felt stigma, with an emphasis on the effects of life experiences on current expectations. One significant limitation of this study, though also its strength, is the focus on the service user perspective. While it is essential to understand this under-researched aspect of healthcare for people with learning disabilities, a complementary understanding of the factors that support or impair the development of therapeutic relationships from the health professional perspective is also necessary, and is worthy of future research. This study has strengthened the argument that structural developments are also needed to promote health facilitation, liaison and professional education carried out by learning disability nurses (see *Implications for practice* for detailed discussion).

### Conclusion

This study arose from a need, in 2008, to evaluate the development of primary health services for people with learning disabilities from the perspective of service users. Following the development of connections and some good interpersonal relationships with service users and service providers, I would now choose to support service users in carrying out their own research, as exemplified by a service-user led study into the Directed Enhanced Service for people with learning disabilities (Michell, 2012). There have been errors of understanding the epistemological stance early on in the process which, combined with delays in access to interviewing service users, contributed to slight deviations from a pure grounded theory data collection and even to a small extent, analysis (particularly related to *Expressing agendas*). Overall though, the essential intention of the constructivist grounded theory approach to “construct an interpretive rendering of the words we study rather than an external reporting of events and statements” (Charmaz, 2006) has been achieved. The model developed from this (see chapter 6 *Towards a comprehensive explanatory model of health consultations – Past experiences and current perceptions in health encounters*) has both originality within the literature and resonance with the service users who took part, and will be useful in developing new research studies and new connections with related research disciplines, and in developing individual health professional practice and planning services for people with learning disabilities. How the findings from the current study fit with the relevant bodies of literature will be discussed in

the next chapter, chapter eight, *Setting the findings in the context of the literature – Implications for future research*.



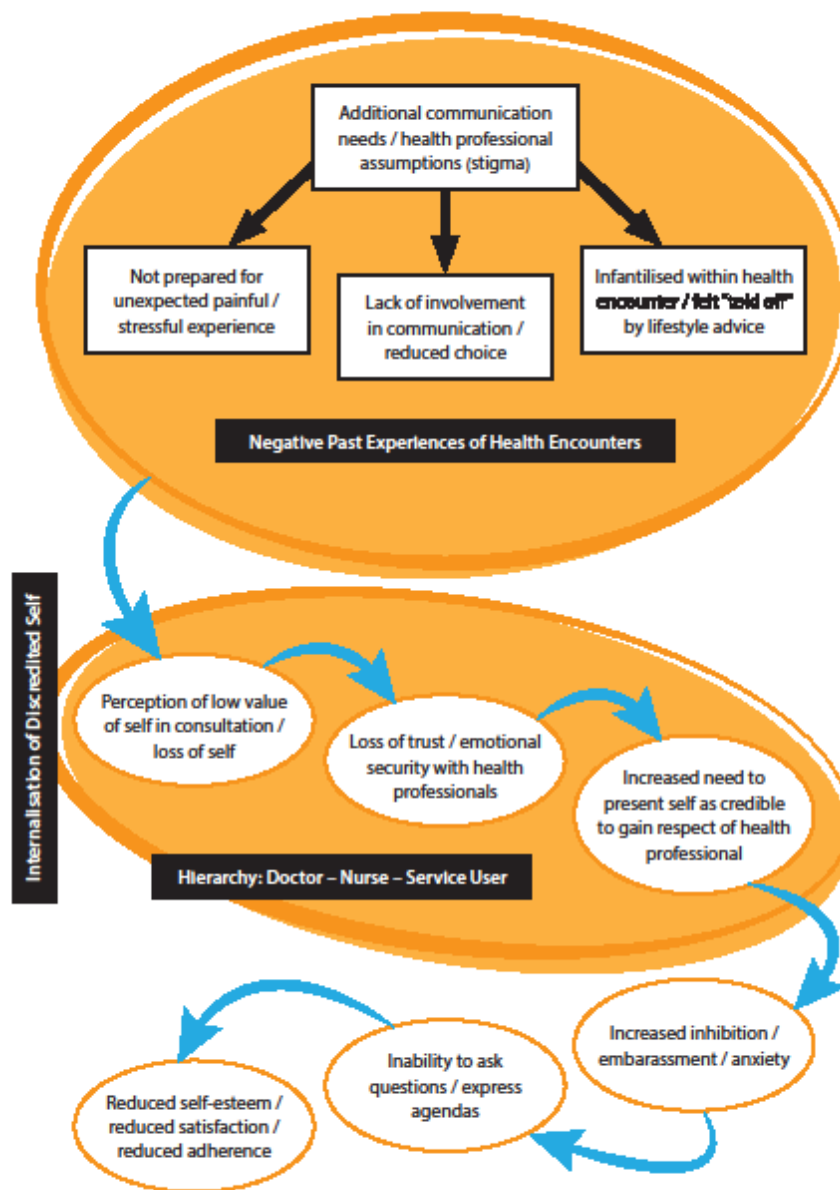


## ***Chapter 8: Setting the Findings in the Context of the Literature – Implications for Future Research***

### ***The Overall Model of Health Consultations for a Person with Learning Disabilities***

The analysis presented within this thesis suggests that people with learning disabilities need to feel trust and emotional security with their health professionals, in order to communicate effectively and engage in their health consultation and self-management. Key aspects of a trusting relationship include the health professional listening, responding to cues, being friendly but valuing of the person, including them in the consultation, and getting to know the service user as a person over time. Previous experiences of not being involved in the consultation, or even included in conversation or given eye contact, but of relying on a relative or paid carer to manage the interaction, effectively reduces the service user's expectations of the need for or desirability of engagement. The health consultation is made more complex by the multiplicity of services used by the person, and by their need for support within the consultation and with health and lifestyle management; this leads to a need for specific approaches and skills, and for a learning disability facilitator/liaison nurse to support access to mainstream services, including educating and role-modelling for health professionals with respect to person-centred communication with people with learning disabilities. There are additional barriers to effective communication and engagement relating to the need for clear explanation and informed consent, the negative psychological effects of some lifestyle advice, the perception that more time is needed, and the effects of anxiety, embarrassment, felt stigma and past experiences in inhibiting interaction within the consultation. These past and recent negative emotions associated with health encounters may increase the perceived need for the person (and their carer) to present themselves as credible within the consultation or to avoid engaging with it altogether, thereby reducing the potential for further damage to their self-esteem. The service user may become infantilised within the interaction through the health professional and/or companion assuming the adult role in order to exchange complex health information efficiently, or because of assumptions by the health professional, and the service user internalises the role and perceives the negative emotions associated with some consultations as being even stronger barriers to their involvement. (See Figure 6: *Model of possible effects of the triadic consultation, with/without health facilitator support* for the possible effects of this triadic consultation in *Relation to literature on triadic consultations* within this chapter).

The negative effects of ineffective or harmful previous consultation interactions on their self-concept and self-esteem within health consultations may produce a powerful barrier to engagement (see chapter 5: *Communication barriers: anxiety, embarrassment and stigma*) which cannot be overcome by a single successful consultation. Indeed, the service user may have to express their feelings to a health professional, and have them accepted and addressed, in order to begin to overcome them; and even then, they would need to develop a secure, trusting relationship with one health professional before they were successfully able to negotiate multiple service providers. This may indicate why several service users valued the support of the health facilitator (see Figure 6: *Model of possible effects of the triadic consultation* for insight into the additional layer of complexity in the consultation experience for the many people with learning disabilities who need support from a relative/companion/carer within the health consultation). In terms of the literature, this model suggests that the current focus on discourse or outcomes from one consultation is over-simplistic, and that the current multifactorial models are inadequate because they do not incorporate the influences of long-term relationships, multiple service encounters, the role of important others, and past experiences on current perceptions, expectations and health outcomes. See model below (Figure 5: *Developing Model of Factors influencing the health consultation experience for a person with learning disabilities*) for an overall view of this process.



**Figure 1: Developing Model of Factors influencing the health consultation experience for a person with learning disabilities**

As Figure 5 shows, the combined effects of multiple possible negative experiences from previous health encounters can lead to a feeling of being discredited within current

health encounters. This, in turn, may result in the person perceiving themselves as of lower value (and status) than the health professional, and being unable to trust them, leading to a need to present themselves as credible in order to gain their respect. By gaining respect, the person preserves “face” (Goffman, 1959) and optimises current and future status and outcomes from the consultation. However, this increased pressure on a creditable presentation of self may lead to inhibitions, embarrassment and anxiety, making it difficult for the service user to ask questions and to express their agendas. This lack of engagement with the health professional in the health encounter would then reinforce reduced self-esteem, reduced satisfaction with the consultation and reduced adherence to advice or health management, since their perspective has not been incorporated into the problem-solving process. The analysis of the data from this study led to links with three main bodies of research literature: health consultations, which are considered in both health psychology and medical literature; triadic health consultations (found in different specialist health consultation literature, associated with specialities such as children’s medicine and cancer care) and the role of learning disability nurses in health consultations (found mainly in the learning disability literature); and the literature on the health needs, experiences and outcomes of people with learning disabilities. Much of the literature on the health needs and outcomes of people with learning disabilities was discussed in the background to this study, which was updated following data analysis. This, and the more recent research on the experiences of people with learning disabilities within health encounters, was mostly found within the learning disability literature, with two notable exceptions in the nursing literature and a primary care journal. This study demonstrates the importance of considering the health consultation experiences and needs of people with learning disabilities both within the learning disability literature and in the context of the wider health consultation and health psychology literature. This section will evaluate the contribution this study has made to the general health psychology and health professional literature on health consultations, with an additional section on the understanding of triadic consultations, followed by an analysis of what it adds to the learning disability literature on health consultations, particularly annual health checks.

### ***Relation to Health Consultation Literature***

A central finding in the current study was that the relationship with the health professional affected all aspects of health and the health consultation (see *Trusting relationships and emotional security with the health professional in the consultation experience*), and that being known and understood by the health professional was essential for a good

relationship. An important corollary of this is that health consultations cannot be comprehensively understood through analysis of one consultation alone, or even through the service user's evaluation of that consultation, because each consultation is experienced, interpreted, understood and acted upon within the context of all previous health encounters. A key aspect of the relationship was the perception that the health professional was listening to the participant. While the use of checklists and computers, which limit eye contact or gaze, have a negative impact on this, the underlying meaning of being listened to is one of feeling that your personhood and perspective are valued. This is a prerequisite of a concordant outcome to health consultations, which is related to service user satisfaction and improved physical outcomes. The current study found a clear relationship between person-centred communication and satisfaction, and evidence that poor communication led to disempowerment and detachment from the consultation, leaving a legacy of mistrust and anxiety about future consultations.

Ethically (Department of Health, 2001), and in terms of adherence to medication and advice (Korsch & Negrete, 1972), the service user's views of the experience are important. It has been argued that psychological problems confound research into patient satisfaction (Simon et al., 2010) and some research has excluded patients with psychological issues from satisfaction assessment (Kinney et al, 1975), but the current study has shown that people with situational anxiety, psychosocial issues, or a dual diagnosis of learning disability and psychiatric disorder, and possibly women, are more at risk of having unsatisfactory consultation experiences, and health professionals may need specific training and education to understand and meet their needs (see *Embarrassment*, *Feeling shy*, *Labels within learning disability*, *Presentation of self*, and *Credibility*). Research focusing on information-giving and understanding within the health consultation finds a strong relationship between understanding and adherence (Ley, 1982), but doctors tend to give more detailed explanations to patients whom they like (Beach et al., 2006). Since doctors also tend to prefer service users who are generally well (Beach et al., 2006), this may partially explain why some service users sometimes did not feel liked, and did not feel that they had received adequate explanations (see *Explanations and understanding in health consultations*). Indeed, while all health professionals need preparation for explanation-giving in their pre-qualifying education, the underpinning theme from this thesis suggests that seeing the world from the person's perspective and caring for them authentically and according to their need is more important. This means that health professionals who are accepting of others, appreciate diversity, and value people for themselves rather than

according to wellness or other pre-conceived criteria, are more likely to develop trusting relationships, and their consultations are more likely to have satisfactory outcomes from the service user perspective, whether or not that person has learning disabilities. Hence, there is a clear link between health consultation literature and the evaluation of health consultations for people with learning disabilities.

Much research into the health professional-service user relationship has used measurable variables to identify strengths and weaknesses in the consultation process. Although some quantitative research has made interesting findings in relation to aspects of the consultation such as liking (Hall et al., 2002), communication style (Cox et al., 2008) and attitudes of respect (Beach et al., 2006), other quantitative research is lacking in theoretical sensitivity and has little to add to our understanding of health consultations (Auerbach et al., 2002; Campbell et al., 2007). Regression analysis of multifactorial non-verbal behaviour and questionnaire studies has only been able to explain a limited amount of variance (Pawlikowska et al., 2012; Peltenburg et al., 2004). This may be partly because there are subtle factors at play that are not easily measurable, and partly because they focus on single consultations, without taking into consideration the participants' preconceptions and interpretations based on previous experiences. The reductionist approach is not completely satisfactory in consultation research because the complexity of health consultations is not easily measured, and subtle variations can cause large differences in outcomes. The current study shows that the relationship between service user, carer/companion and health professional is key to overall satisfaction with the consultation, and that although specific identifiable aspects such as listening and picking up on cues seem to be measurable, they are at least partly dependent on the service user's expectations, influenced by the carer, and how they affect their engagement with and perceptions of the process.

Future research into health consultations could explore commonalities in experience with other marginalised groups in society, such as older people, people with mental health disorders, people labelled as belonging to the black minority ethnic community; and explore their views on which aspects of the consultation are important to them and why. Studies into adherence and satisfaction with these groups would contribute further to the health psychology literature, and it might be possible to carry out integrated research studies involving people from the general population and people with learning disabilities to establish similarities and differences.

***Relation to Literature on Triadic Health Consultations and the Roles of the Companion and the Health Facilitator in the Health Consultation***

People with learning disabilities have a higher-than-average chance of also having a psychiatric disorder (Werner & Stawski, 2012), are an ageing population and are now being included into mainstream services. Consequently, they are more likely to receive care from multiple care providers (Carnaby et al., 2011). This lack of continuity makes them more dependent on other people to support them in consultations and improve communication across specialities, yet specialist services expect referring agencies to understand their language and processes in order to refer to them (Leyin, 2011). Parents often undertake this role, although it can be stressful (Castles et al., 2012) and many older service users have parents who are ageing or do not have close relatives to support them. This leaves service users vulnerable to increased anxiety related to change, exacerbated by negative past experiences of healthcare, increased sensitivity to new faces or change due to autism or other mental disorder, and a feeling of not understanding what is happening and not being in control (see *Trusting relationships and emotional security with the health professional in the consultation experience*). Health professionals, who may have little experience in triadic consultations or in the care of people with learning disabilities, are expected to address the physical health needs of service users while maintaining satisfactory communication and relationships with both service user and carer, and gathering information to make assessments and explain healthcare options.

The literature on triadic consultations in adults is somewhat disjointed (Laidsaar-Powell et al., 2013), but discussions in children's health literature (Cahill & Papageorgiou, 2007) and learning disability health check literature (Ellingson, 2002; Perry et al., 2013) suggest that health professional conversation with parents and carers can sometimes lead to the service user feeling excluded from their consultation. However, Cahill and Papageorgiou (2007) identified that, if the health professional took the lead in involving the child, the parents would also include them in the decision-making process. The finding from the current study that the parent/carers sometimes takes on the parent role in order to provide the health professional with the information they seek, and to appear credible in order to optimise the consultation experience and outcomes for the service user, suggests a mechanism by which this also occurs in consultations involving someone with learning disabilities. Consequently, the adult-adult-adult triadic consultation may require the health professional to take the lead, yet previous experiences may lead the service user to expect to take a more passive role (see *Involvement in communication/inclusion; Informal*

*support*). The symbolic interactionist model of previous experiences shaping current expectations of the consultation is sharply thrown into focus regarding the inclusion of the service user, their engagement as an adult, and their levels of self-confidence and self-esteem in order to achieve this.

The health professional cannot force the service user or their companion to adopt a tripartite adult interaction (see Lindsey's response to such an attempt in *Involvement in communication/inclusion*). However, if health professionals seek a more equal relationship within the consultation, by which the service user takes more responsibility within the consultation and regarding health behaviours, then they have a responsibility to develop the conditions under which the service user can gain the expectations, skills and confidence to achieve this. This requires time, expert communication skills and, as seen from the overall model, the development, over time, of a trusting relationship with the service user. For many people with learning disabilities, any expectation that they can actively engage in the consultation and take ownership of their health is unrealistic unless health professionals develop trusting relationships with them (and their carer) over time, have a good understanding of their communication needs, listen for and respond positively to their cues, gradually habituate them (and their carer) to higher levels of understanding and involvement, and value them as an individual. This requires both reflection on their attitudes towards the person and emotional labour on the part of the health professional. The current study has shown the health facilitator to be successful in helping service users to achieve a higher level of adult engagement with the health consultation process and in managing their own health, provided they know the service user (and carer) well, and liaise with all professionals involved in the person's care. However, not all service users identified that they had a health facilitator, and some of them had only met them when having annual health checks.

Perry et al. (2013) has identified that there were some issues over privacy, particularly about sexual and reproductive health issues and, while there was a suggestion in the current study that this was the case, participants with parents generally preferred to go with them, except where they felt they were not able to discuss sensitive issues. Mostly, though, the current study identified that the relative wanted the health professional to include the service user and made efforts in the consultation to promote the personhood of the service user, a role that has not previously been identified in the literature. It has been argued that models of triadic consultations and the depth of analysis related to them are inadequate and that more research is needed in this area (Laidsaar-Powell et al., 2013). The



current study has added to our understanding of the complexity of the companion's role in co-interpreting the health consultation with the service user, balancing promoting their personhood with presenting themselves and the service user as credible in order to optimise the relationship with the health professional, and in explaining and supporting the transmission of relevant health information to the service user (See Figure 6 below for *Model of possible effects of the triadic consultation, with/without health facilitator support*). The depicted model shows how a health facilitator can bridge the gap between the service user or service user-carer dyad and the health professional who may not know the service user well. Without the health facilitator, the previous possible cycle from previous negative experiences to a discredited view of the self, leading to lack of engagement within the health consultation and failure to establish a relationship with the health professional is shown. Where the health facilitator supports the service user or service user-carer dyad, the health facilitator's credibility with the health professional enables them to promote the personhood and credibility of the service user. Consequently, increased understanding is achieved and more concordant outcomes reached, leading to increased self-efficacy and adherence and a more creditable view of the self within health consultations, at least with the health professional involved (See Figure 6).

This study provides an opportunity for connecting this model of triadic consultations with emergent models in mainstream consultation literature. It also suggests the importance of specific education for health professionals related to communication and relationships within triadic consultations, and provides the opportunity for research into the best ways of achieving this, as well as re-consideration of emotional labour within healthcare. This study has significantly added to the service user perspective on the effectiveness of the health facilitator, and suggests the need for further research into that role in order to identify the systems, role resources, skills, knowledge, behaviours and attitudes that are required, with a view to developing more health facilitators and acute liaison nurses within primary care services.

## Role of other and service user involvement in health consultation

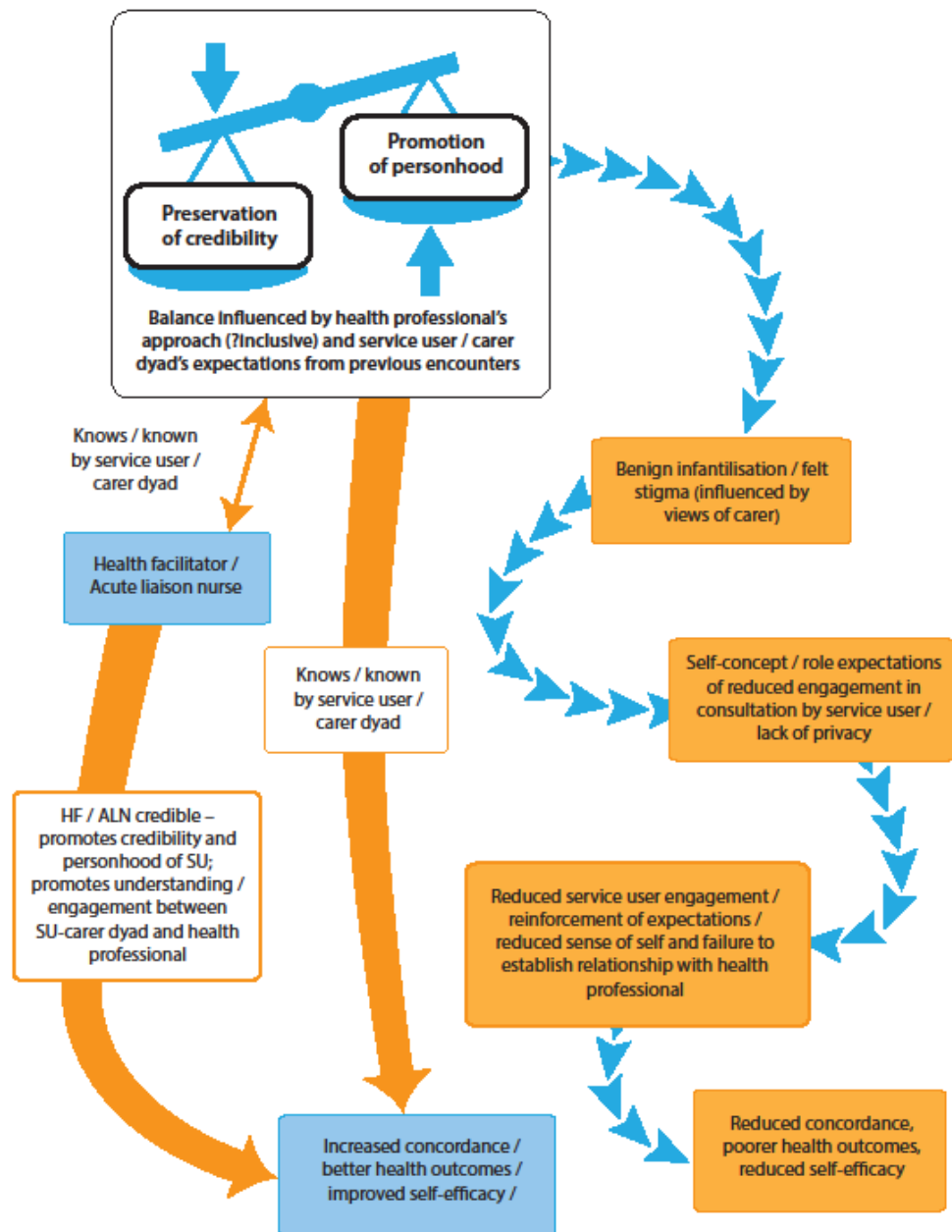


Figure 6: Model of possible effects of the triadic consultation, with/without health facilitator support

### ***Relation to Literature on the Health of People with Learning Disabilities***

Many of the reports and studies that informed the development of this study were discussed in *Health needs and inequalities and the development of service provision for people with learning disabilities*, updated following the data analysis, to make the thesis coherent. The White Paper *Valuing People* (Department of Health, 2001) clarified the requirements for mainstream services to meet the health needs of people with learning disabilities by making reasonable adjustments and initiating health action plans, health checks and health facilitation to promote integrated working. A number of reports highlighted the inadequacy of healthcare, inequalities in health, and increased morbidity and mortality in people with learning disabilities, identifying marginalisation, discrimination and diagnostic overshadowing as issues causing unnecessary deaths and distress to people with learning disabilities and their families. The focus of these reports, though, was on improving access to health service provision, rather than on the quality of the service user-health professional interaction; and reasonable adjustments focused on provision of annual health checks, the use of plain English, provision of easy-read leaflets and a separate waiting area, and the need for staff to contact a relative, carer or advocate when someone with learning disabilities was admitted.

Much of the learning disability literature has focused on evaluations of specific services for people with learning disabilities, such as health facilitators, acute liaison nurses, and health and lifestyle groups, as well as highlighting failings in mainstream services and a lack of reasonable adjustments for people with learning disabilities, and discussing the most suitable workforce or service provision to provide the care that service users and their carers want. They focused on evaluating the effects of supportive services, such as health facilitators, or on the more behavioural aspects of health encounters, such as talking directly to the service user, explaining procedures, using easy-read leaflets or providing annual health checks. Several studies took the essentialist perspective that the data were based in reality and, while this provides a reassuringly concrete analysis of the health consultation, less open to subjective interpretation by the researcher, it produces a greater emphasis on behavioural or environmental aspects of the experience. Consequently, the emotional richness and meaning of the consultation are not explored in depth. However, this type of study is seen as “factual” and may be regarded as useful by policy makers and health professionals, as it leads to generalisable recommendations that can be quantitatively audited. For example, people with learning disabilities are less likely to tell the doctor when they have pain, so the doctor should ask them if they have pain (a

component of the Cardiff Health Check). Nonetheless, that does not explain why they are unable to communicate their needs to the doctor.

By contrast, the current study has analysed the more relationship-focused aspects of health consultations. It provides a deeper analysis of the complexities of the processes underlying triadic consultations. It also explores how service users view themselves within the consultation, finding that their feelings of cognitive inadequacy, infantilisation, anxiety, and fear of embarrassment and loss of dignity inhibit their involvement, and these feelings are reinforced through a continuing cycle of negative expectations influencing the next encounter. This finding adds significantly to the learning disability literature, which has focused more on negative behaviours on the part of health professionals, promoting the perspective that reasonable adjustments are generally made by adjusting behaviours. , The current study questions such a simplistic analysis, and identifies a need for attitudinal change and emotional labour to develop a trusting relationship which, over time, can improve the quality and outcomes of health consultations for the person with learning disabilities, and promote their engagement in the process. It also highlights the importance of health checks being shared across all health providers within the GP practice, to avoid it becoming marginalised within the mainstream, and suggests a need for further education and development to support that.

The current study did not explicitly ask about perceived stigma or discrimination, focusing more on the meaning of the experience for the person. The findings clearly relate to literature on service user-health professional communication within the general population. However, although people with learning disabilities have similar needs to people within the general population, they have also felt stigma and may more easily be convinced that misunderstanding or a lack of satisfaction is their “fault”, resulting in them having lower expectations from future consultations. Issues of embarrassment around sexuality, and anxiety over being examined or having intimate subjects discussed by or in front of a person of the opposite gender, are particularly difficult for people with learning disabilities. The study on experiences of contraception by McCarthy (2009) has shown the importance of interviewing participants about experiences that are difficult to discuss for various emotional, social and political reasons. It accessed important insights into the way in which women with learning disabilities have their needs related to sexual relationships, sexual health and contraception managed in a way that excludes them from the decision-making process and reinforces their vulnerability to sexual exploitation without attempting to address this in other ways. The current study attempted to explore needs related to

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sexual and reproductive health issues, but service users were very reluctant to discuss them, and I would have needed to build up a trusting relationship over time to be able to discuss it in more depth. Future research in this area could ask service users about their hopes, expectations and experiences of sexual and reproductive health needs, including advocacy, education and understanding of intimate relationships, but strategies would need to be devised to enable access and develop trust with service users and gatekeepers to access the depth of evidence needed.

People with learning disabilities are also more at risk of anxiety through lack of familiarity and understanding related to language, processes and procedures, as well as because of specific sensitivities to stimuli, particularly in relation to autism. Where previous negative experiences have been poorly understood, the potential for future anxiety increases, and people with learning disabilities in the current study had difficulty in making sense of their past experiences, leading to strong barriers to engagement with current healthcare. The importance of previous health encounters in the expectations, understanding of, and satisfaction with, the next one, highlighting the importance of building and maintaining person-centred relationships with the service user and their carer, is a key finding in relation to all the literature. It contributes to the model of the health consultation as being an iterative experience, not just constructed in the moment, requiring knowledge of the understanding people have of past experiences in order to understand their current thoughts, feelings and behaviours. This explains the importance of the learning disability nurse, with their knowledge of the lives of people with learning disabilities, and a focus on the holistic understanding of the individual within their social relationships. However, it also demonstrates that, if people with learning disabilities are to have equity of access to mainstream services, then, in addition to the expected reasonable adjustments, all health professionals will need valuing and respectful attitudes towards all service users, which require experience, emotional labour and reflection, as well as the development of a relationship with the person. Thus, the breakdown of service by speciality has educational, emotional labour and time implications for all health professionals if they are to achieve this person-centred approach to consultations. In order to avoid the development of another parallel service, and to promote the engagement of people with learning disabilities in their encounters with a multiplicity of service providers, there needs to be more awareness, shared experience, cross-disciplinary education and flexibility in the workforce, so that there is greater learning disability expertise in mainstream services, and

learning disability professionals are equipped with the skills and knowledge to support and understand care across different disciplines.

The current analysis focused more on expressions of feelings, communication, relationships with others in the consultation, and views of the self. This was used to develop an understanding of the often intangible or incompletely documented reasons for people's satisfaction or otherwise with health consultations. The current study identified that reasonable adjustments are more than simply providing health checks, with longer appointments, shorter waiting times and easy-read leaflets. The key finding is that factors such as anxiety related to health encounters, exacerbated by previous experiences that may have lowered the trust of people with learning disabilities of health professionals in any mainstream services, require health professionals to invest both time and emotion in developing a relationship with the service user and their family or other carers in order to overcome barriers to communication and inclusion in their healthcare and promote concordance.

### ***Reflections on Findings***

This study has added a unique insight into the meaning of the service user experience of health consultations, and how it affects their self-concept, emotional well-being and health outcomes. Through an in-depth analysis of the experience from their perspective, and by using a grounded theory approach to minimise the influence of other research into the data gathering and analysis stages, this study has shown that people with learning disabilities have insight into other people's views of them, and need to be valued and respected, listened to and involved in their health consultations in the same way that other people do. It has shown that they need consistent, trusting relationships to enable them to engage with health consultations, and that health professionals need to develop their skills and understanding related to managing triadic consultations. It has also shown the importance of learning disabilities health facilitator in supporting service users and professionals to communicate about health. One reason why learning disability nurse health facilitators are so effective may be due to their understanding of the perspective of the service user, and ability to present the person to the health professional with authority and respect for the individual. Finally, it has shown that embarrassment, anxiety and past experiences of healthcare, combined with the need for better explanations and more focused attention to the person and their perspective, add extra barriers to communication that the health professional needs to understand and overcome in order to improve health consultations

for people with learning disabilities. The historical adoption of a parallel service has reduced the opportunities for healthcare professionals, particularly GPs, to care for people with learning disabilities, and one of the potential disadvantages of the DES is that service users are marginalised within mainstream services and seen by a designated person, except in acute situations, where the health professional may be little better equipped to support them, and will not know them as a person. This study has shown that respect and person-centred consultations are more achievable within a trusting relationship, and that service users are better able to engage and express their needs in that situation. Therefore, unless the DES is undertaken to promote the understanding and engagement of all health professionals within a GP practice, and they undertake relevant educational support (possibly by the health facilitator), there may be situations where health consultations continue to be unsatisfactory, despite the reasonable adjustment of annual health checks.

The use of the symbolic interactionist perspective in the current study has shown how participants' expectations of consultations are profoundly influenced by all their previous experiences of healthcare, identifying the importance of a lifetime perspective in understanding the needs of the service user. It illustrates the importance of understanding current consultations in the context of past experiences, and emphasises the need to build a relationship over time with service users in order to earn their trust and allow them to engage with the process. This process of a downward spiral of expectations and disengagement may also account for some of the continuing inequality in health outcomes for people with learning disabilities. The current study also explored why people might feel anxious or embarrassed, and that issues that are apparently procedural, such as needle phobias, have causes and possible solutions grounded in the meanings, experiences and emotions related to health consultations. This is important in terms of helping health professionals to understand what service users need from the consultation, and what they mean by "good" communication, and also in supporting them to appreciate the personhood of service users with learning disabilities, especially if they have little experience of meeting them.

The relationship between the effects of the experience and expectations of people with learning disabilities and their carers should be a focus of future learning disability health outcomes research. Future research needs to develop the relationship between learning disability health research and other service user experience and health psychology research, to promote development of this fertile research area. Health consultation research should explore the relationship between people's past health encounters and

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their current satisfaction with health consultations. Specific aspects of healthcare related to sensitive issues, such as sexual and reproductive health, need to be more open to study, but require access and the development of trust in order to really understand the underlying processes and emotions involved. Where acute liaison and health facilitator services are provided, these should be assessed from a service user experience perspective, in order to demonstrate their value and sustainability. Inclusive research, where service users are supported by the researcher, can now be developed by the researcher and this should be used as one strand of service user-focused research into health consultation studies for people with learning disabilities. I will develop current links to initiate this as part of my future research into the healthcare of people with learning disabilities.

### **Conclusion**

Although the findings from this study are grounded in the data, much of the interpretation of its meaning has been constructed from the emotional responses of participants to situations and the meanings they attached to them. Consequently, this interpretation is based on my understanding of interactions with service users, and my constructed world view, based on my own perspectives. Although good practice was identified, and service users made positive comments about their care, when people were interviewed individually or in pairs they often revealed a sense of underlying anxiety and disengagement with health consultations. This analysis shows that, even where individual health professionals are person-centred and approachable, the interpretation of past experiences, lack of continuity and other communication barriers can make the development of positive relationships for better health outcomes challenging. Nonetheless, the model also suggests ways of meeting these challenges for professionals, educators and service managers (see *Implications for practice*), and new areas of research in order to develop a more detailed model of health consultations for people with learning disabilities and their relationship to other health consultation research.



## **Chapter 9: Implications for Practice, Education and Research**

Despite the statements of intent and initiatives to improve the health of people with learning disabilities since *Valuing People* (DH, 2001) was published 13 years ago:

*Excess morbidity and mortality among mental health and intellectual disability patients persists, while stigma and discrimination towards these groups remains apparent. It is also clear that the commitment to address this problem falls short of action taken on physical health conditions*

(Hollins, BMA Science and Education department, & BMA Board of Science, 2014, p4)

The current study has explored the effects that health encounters have had on the self for people with learning disabilities, and how these effects resulted in reducing their engagement with the health consultation process. The use of this symbolic interactionist approach within a grounded theory study, a methodology suited to exploring new phenomena, has not previously been used in this context of mainstream health encounters for people with learning disabilities. It has produced an original analysis of the health consultation experience from the service user perspective, thereby identifying possible mechanisms by which health checks and related initiatives intended to improve the health of service users have not done so.

The role of the health facilitator has been seen as beneficial in some of the grey literature (Department of Health, 2013a; Department of Health et al., 2013) informing learning disability practice and policy. However, although the service has been positively evaluated by health service provider colleagues (Brown et al., 2012; Castles et al., 2012) the ways in which the role of the health facilitator improved outcomes from the health consultation had not been explicated and supported with data from the service user perspective. Similarly triadic health consultations for people with a learning disability have been discussed in relation to the importance of inclusion of family (Broussine & Scarborough, 2012), and conversely the need for privacy and self-determination (Perry et al., 2013), but this is the first paper to determine mechanisms by which such encounters affect the outcomes of consultations. The role of the health professional in supporting the companion to include the service user in the encounter has been identified as important for promoting their inclusion and engagement with the process.

Fundamentally, the role of previous experiences on current engagement with health consultations had not been evidenced prior to this study. This identifies the role that previous stigma, enacted upon or felt by the service user and their family, has on inhibiting their engagement with health consultations. This perceived stigma may stem from old experiences, either direct or learned from family members (Scamber & Hopkins, 1986). Participants' perceptions of discrimination against people with a learning disability (You and Yours, 2012) reinforced fears of being discreditable by virtue of disability (see *Psychosocial Healthcare/Needs/Labelling and Stigma*). Unless the health professional is aware of this felt stigma, and the way in which it inhibits communication, they are unlikely to be able to overcome its effects. The findings on health professional-service user relationships and the qualities that were essential for a satisfactory outcome for the service user related closely to findings in the health psychology literature (Clucas et al., 2011; Malpass, Kessler, Sharp, and Shaw (2011); Martin et al., 2005). Nonetheless, some concepts, such as the importance of maintaining respectful relationships over time, and being known by the health professional, had not been explored in recent literature (Ridd et al., 2009). The recent focus on detailed analysis of types of utterance and body language (Pawlikowska et al., 2012; Roter & Larson, 2002) necessarily omitted some of the cognitive and felt aspects of the consultation from the analysis, so this thesis has updated older research and shown how previous experiences of relationships with health professionals, as interpreted by the service user with their relative or carer, influence the outcomes of the consultations. In view of these findings, it is important that health professional policy and practice adapts if the inequalities in health between service users with learning disabilities and other service users are to be reduced. In this concluding chapter, implications of this thesis for practice, education and policy are discussed in relation to the findings from the current study.

The first major theme of trusting relationships and emotional security with the health professional identified that previous experiences of a reduced sense of self within the consultation had led to some service users disengaging from the process. The service user and their companion may have focused on the need to present themselves as creditable and credible to the health professional at the expense of being fully open. Therefore, the health professional should be aware that service users and their carers may have had disappointing experiences of health consultations in the past, and may not feel able to engage fully and openly with the process immediately. Health professionals should provide the opportunity for service users and carers to talk about past experiences to gain insight into their perspectives. It requires patience and time for the relationship to develop.

Similarly, service users sometimes had difficulty in expressing their concerns, so it is important to hear and respond to cues. Listening to the agendas expressed by the service user and their companion may uncover health needs that are not identified within the biomedical approach, and also supports a trusting relationship. In the health check, it is important to allow time and listen carefully for the service user – carer to express their priorities and personhood. This is important throughout the information collecting process for identification of health needs, as the health professional will gain greater understanding of need and develop more trust, than if they are perceived to be focused on form-filling.

Within this theme, it was also found that people with learning disabilities were sensitive to health professionals' attitudes towards them, and need to feel respected. While they liked people to be friendly, this did not automatically generate trust. Consequently, although simpler language and more explanation may be required, communication with a person with learning disabilities should be genuine and respectful, not simply friendly. However, service users sometimes felt shy or had difficulty understanding conversation within the consultation, so using a pre-prepared health action plan would help them to express their agendas. Detailed guidance on health checks is given elsewhere (Hoghton, 2010), but it is essential that the service user is involved in developing their health action plan to be considered within the consultation. The health professional should seek to engage in this process and use the documentation where possible. When giving information or advice, easy-read leaflets were identified by service users as a necessary resource. However, they needed guidance on which leaflets to access, and many had to be downloaded from specialist websites. Not all health professionals provided this service, but even the use of easy-read leaflets was not sufficient, without other forms of communication, to support autonomy in health care. One practitioner in this study used bottles of water to demonstrate how much a service user needed to drink, making understanding and self-management easier. Overall, health professionals in all settings need to develop communication strategies to aid understanding for people with learning disabilities. Some health advice was seen as aversive by service users because it was not adapted to address their needs and readiness to modify lifestyle behaviours, and health professionals' expectations of their self-efficacy were higher than they were used to. This highlighted the importance of engaging with both the service user and their companion in order to avoid distress and produce a shared understanding.

The theme of the role of the other in health consultations addressed the frequent need for people with learning disabilities to be accompanied when accessing health care, as well as

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their increased use of multiple services, resulting in complex interdisciplinary working and communication with all parties. Some participants identified the need for privacy to discuss personal concerns. This may not be appropriate in the first consultation (see above), but once trust starts to develop, it is appropriate for the service user to have the opportunity to discuss any embarrassing issues without the companion present. Some form of chaperone may be required – where possible, someone trusted by the service user. It was found that a companion who knew the service user well was better able to represent their personhood, and more useful in relating signs and symptoms of illness. Interaction with the carer was a key influence on the service user's perception of and confidence in health professional. If the service user or their companion felt that the companion's knowledge or insight was not valued, then the service user lost confidence in the health professional. By developing a relationship with the service user and their relative/advocate/key worker over time using person-centred communication, the health professional could enable the service user to feel more confident in taking part in the consultation. The current study has shown that is important to promote involvement of the service user at their own pace, gaining the trust of both the service user and their companion.

Within the GP practice, some service users perceived a hierarchy, suggesting they sometimes felt less confident when seeing a doctor with a higher status. In addition, it is currently advised that there should be a clinical lead for health checks in GP practices (who updates and liaises on current best practice). However, participants' experiences suggested this often meant that health checks were carried out by one nurse, and when they had an acute health need, the doctor did not know them as well, or have as much experience in meeting their needs. Where participants did not feel valued in health consultations, they lost confidence in the health professional. To manage this, each health professional should have a small number of service users with whom they develop a relationship with over time. Where the relationship is not satisfactory, changes can be made. Where the usual practitioner is not available, at least they will have some experience and knowledge of communicating with people with learning disabilities and their carers. All health professionals need to understand the needs of service users with learning disabilities in order to make reasonable adjustments – health facilitators and acute liaison nurses have the expertise to advise on and support health professional development. They may help with relationship development, communication and liaison, but it is essential for all health professionals to take on the direct care role to avoid development of another parallel service for people with learning disabilities.

Encounters with multiple service providers, to access mainstream services, meant that service users did not always know the person they were seeing, why they were seeing them or what their role was. This reduced the effectiveness of the different consultations. Family members or paid carers took on the role of co-ordinating communication, but service users sometimes found that paid carers did not have the information the doctors needed. Where service users are supported by paid carers, there should be a named person who consistently collates health information, supports them with their health action plan and attends health consultations with them. This would promote continuity of care and communication of health needs and observations. It would also help with the development of trusting relationships and ensure the service user's agendas are expressed. Personal health records might help with transparency and multi-professional communication, enhancing the service user's sense of control over their own health and feeling of being valued within the process. Health facilitators were regarded as helpful by participants because they helped them to prepare for and understand consultations, reducing their anxiety and helping them to take control of their health. The health facilitator was important for helping people to change their health behaviours without discrediting their identity, and for enhancing their role within the health consultation.

The third major theme identified anxiety, embarrassment and stigma as barriers to communication. These occurred either within the consultation or due to anticipated problems caused by previous experiences or learned attitudes. The fear of pain or other physical discomfort, possible inability to present themselves in a creditable way, or being treated with disrespect were all identified as barriers. These fears resulted in service users either disengaging from consultations or feeling unable to express their agendas. This had serious implications for the effectiveness of health encounters, identifying a key pathway by which, despite annual health checks, service users with learning disabilities continue to experience health inequalities. Participants felt anxiety for a number of reasons, including: previous experiences; fear of the unknown; fear of loss of control or loss of face; hypersensitivity and hyper-awareness. Aspects of the consultation that caused most anxiety for participants included blood tests, examinations, undressing and disclosure of concerns or information that was felt to be discrediting, such as mental health issues, epilepsy and sexual activity. Several strategies and aspects of the consultation were found to enhance communication reduce and reduce anxiety. Fundamental to these was a trusting relationship with the health professional. However, the strategy of habituation – familiarity with person, place, equipment and procedure was also very important, particularly for

service users with autism. In practice, this may involve gradual introduction to equipment, taking home a disposable speculum, for example. In addition, it was important for participants to understand what a procedure was for, and what was going to happen. This involves the health professional ensuring that they always explain what they are going to do before they do it, in clear and simple language, and checking understanding and consent, as well as giving the opportunity to ask questions. Participants needed to trust that the health professional would not do anything against their will, and to feel fully informed and in control. This was particularly important for people who had previously experienced institutional care and experienced treatment without consent. Support from the health facilitator and the use of easy-read materials were found to be helpful in aiding understanding of consultation experiences and expectations

Certain aspects of the health consultation were more difficult for service users than others, particularly the ability to discuss sexual health issues. Limited opportunities for privacy and felt stigma related to expression of sexuality conflicting with the need to be seen as creditable, created additional barriers. Hence, some service users identified their reluctance to inform health professionals about their personal and sexual behaviours. Smear testing, in particular, raised anxiety and led to reduced take-up of screening services. Contraception without support for sexual choice and rights reinforces the vulnerability of women with learning disabilities, but there was a clear taboo for some of the female service users around discussing sexual relationships. Service users needed expert advice and support, but service providers need to ensure that they make all reasonable adjustments, including being non-judgemental. Primary care health professionals should ensure that they ask about sexual and reproductive health, go through relevant easy-read leaflets with service users and discuss referral with service user (and carer or advocate/health facilitator as appropriate).

This research identified a clear need for all health professionals to develop their proficiency in understanding and meeting the health and communication needs of people with a learning disability. Education raises awareness, changes cultural attitudes and gives service users, carers, health professionals and service commissioners confidence in the abilities of health professionals to address inequalities in care. Health facilitators with a dual qualification have greater knowledge of different disciplines, and may liaise more effectively to break down barriers in health consultations. However, the learning disability nurse is needed to educate and support other health professionals in their communication with people with learning disabilities. There is an acute shortage of learning disability

nurses (Glover & Emerson, 2012), so education needs to be more flexible to address the deficit. The shortage of learning disability nurses suggests that, as well as increasing learning disability nurse posts and education places, research into the feasibility of providing “top-up” learning disability nurse education for adult and psychiatric nurses, and qualified social workers might be useful. This would enable them to carry out dual roles, and also to improve the standing and knowledge of learning disability care across all fields of health and social care. It would help to provide the rapid increase in personnel needed to achieve the goal of an acute liaison nurse in every hospital and, as would be suggested from this study, for every GP practice to be linked to a health facilitator. Health professionals should have access to part-time and distance learning education about learning disabilities. In addition, it should be easier for nurses to gain a registration in another field, to provide better support within mainstream services, to promote interdisciplinary working dual roles such as health facilitation, and to produce a flexible workforce. Short updates for professionals with older qualifications could be introduced to reduce the loss of qualified nurses from the NHS and from nursing.

The current study has shown that evaluation of health care from the service user perspective is essential for understanding the processes by which consultations can be made more (or less) effective. It has also shown that, while ethical considerations are complex, service users can be supported to give informed consent to participate in health evaluation research. However, it is difficult for the outsider researcher to gain access to service users without the assistance of health professionals, so it would be good practice for health professionals to aid research into this area, in order to be transparent and open to scrutiny (Francis, 2013). Since the current study identified the importance of seeing the world from the service user perspective, future research should support service users to identify, research and disseminate findings in accordance with their own concerns.

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## ***Appendices***

## ***Appendix 1: CIPOLD/ Improving Health and Lives learning disability inclusion criteria***

(Confidential Inquiry into premature deaths of people with learning disabilities, 2014)

**"Adults will be considered to have a learning disability if any of the following conditions are met:**

- 1. When a child they were identified within education services as having a Special Educational Need (SEN) associated with 'moderate learning difficulty', 'severe learning difficulty' or 'profound multiple learning difficulty'.**
- 2. They attended a special school or unit for children with 'moderate learning difficulty (or mental handicap)', 'severe learning difficulty (or mental handicap)' or 'profound multiple learning difficulty (or mental handicap)'.**
- 3. When a child they scored lower than two standard deviations below the mean on a validated test of general cognitive functioning (equivalent to an IQ score of less than 70).**
- 4. As an adult they scored lower than two standard deviations below the mean on a validated test of general cognitive functioning and there is good evidence to suggest that they have had difficulties in learning since childhood. Care should, however, be taken when considering the results of tests carried out in English on adults for whom English is not their first language, or where the person is experiencing disrupted mental health at the time of the test.**
- 5. They have been identified as having learning disabilities on locally held disability registers (including registers held by GP practices or Primary Care Trusts) or by relevant Read Codes in health information systems.**
- 6. They report having significant difficulties in literacy and numeracy and there is good evidence to suggest that they have had these difficulties since childhood.**
- 7. They screen positive for learning disabilities using a validated screening test impairments of vision, hearing and movement as well as other problems like epilepsy and autism.**
- 8. In response to survey questions, they identify themselves as having a long-term illness, health condition or disability associated with 'learning disabilities' (or equivalent term) and have low educational attainment (equivalent to no GCSEs at grade C or above)."**

## Appendix 2: Ethics Approval – Study Design 1



### National Research Ethics Service North West 1 Research Ethics Committee - Cheshire

Research Ethics Office  
Victoria Building  
Bishop Goss Complex  
Rose Place  
Liverpool  
L3 3AN  
Telephone: 0151 330 2070  
Facsimile: 0151 330 2075

25 January 2010

Mrs Hazel M Chapman  
Senior Lecturer  
University of Chester  
Faculty of Health & Social Care  
University of Chester  
Parkgate Road  
CHESTER  
CH1 4BJ

Dear Mrs Chapman

**Study Title:** Agendas, experience and health outcomes related to the primary health care consultation for people with a learning disability - exploration and evaluation  
**REC reference number:** 10/H1017/2  
**Protocol number:** 2.0

The Research Ethics Committee reviewed the above application at the meeting held on 14 January 2010. Thank you for attending to discuss the study.

#### Ethical opinion

The members of the Committee present gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.

#### Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

#### Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

*For NHS research sites only, management permission for research ("R&D approval") should be obtained from the relevant care organisation(s) in accordance with NHS research governance arrangements. Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>*

This Research Ethics Committee is an advisory committee to North West Strategic Health Authority

The National Research Ethics Service (NRES) represents the NRES Directorate within the National Patient Safety Agency and Research Ethics Committees in England

### ***Appendix 3: Patient Information Sheet – Study Design 1***

We would like to invite you to take part in a research study. We need to ask



your permission to take part in this study, so we need you to bring your trusted relative, advocate, carer or friend with you to make sure that this is fair and



that you understand everything. Before you decide,

you need to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully.

Talk to others about the study if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part. Thank you for reading and talking about this.

#### **What is the study for?**



Your doctor wants to make sure that people with a learning disability get health care that meets their needs.

I am an independent researcher at the University of Chester. I want to find out what your health care needs are and how well you think they are met.

#### **Why have I been chosen?**

You have been invited to take part in this study because you are being



offered a new health check service for people with a learning disability and we would like to see how well it works.

## Do I have to take part?



No. If you do not want to be part of the study, it will not make any difference to you or your health care. If you do want to take part now but decide, later on, that you do not want to take part, that will be fine and will not make any difference to you or your health care. If you would like to take part, you will be given this information sheet to keep and asked to sign a consent form or have your verbal consent confirmed by the trusted friend or relative you have brought with you.



## What will happen to me if I take part?

If you want to take part, we will give you this information sheet and ask you to sign a consent form or record your verbal consent. I will talk to you before you see the doctor or nurse to ask you what your health needs are. Then I will record you and the doctor or nurse



talking about your health (just your voices). Then, up to four days later, I will ask you to tell me about your ideas about seeing the nurse or doctor and how well it met your needs. At the end of the study, I will invite you to a meeting with other people who have taken part, to talk about what we have found out so that you can make comments and suggestions about anything from the study. I will record all these conversations.

## What are the possible risks for me?



The possible risks of this study for you are that it could make you feel uncomfortable or distressed at sharing any of this information with someone you do not know. If you feel that way, you should not take part in the study, or you should inform the doctor, nurse or researcher that you want to leave the study.

No one will know what you have said as an individual – when we write about the study, everyone who takes part will be anonymous (not have their real name).

### **What are the possible benefits to me?**

We cannot promise any benefit to you, but by taking part in the study, you might help to improve healthcare for people with a learning disability in the future. You might enjoy the opportunity of sharing your experience.

### **What if something goes wrong?**

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee to protect your safety, rights, wellbeing and dignity. This study has been reviewed and given favourable opinion by Liverpool Research Ethics Committee.

This research study is supervised by the University of Chester in consultation with the Western Cheshire Primary Care Trust and the Cheshire & Wirral Partnership. There is no financial payment to the Trust or individuals within the Trust involved in this research.



If you have any questions, please ask the researcher (Hazel) when you come for your appointment, or telephone her on 01244 311626 or 511195 or e-mail her at:

[h.chapman@chester.ac.uk](mailto:h.chapman@chester.ac.uk).



If you have concerns or complaints at any time about anything to do with the study please contact:

Hazel Chapman 01244 51162 [h.chapman@chester.ac.uk](mailto:h.chapman@chester.ac.uk) or

Andrew Lovell 01244 511631 [a.lovell@chester.ac.uk](mailto:a.lovell@chester.ac.uk) or

Ros Bramwell 01244 511477 [r.bramwell@chester.ac.uk](mailto:r.bramwell@chester.ac.uk) or

Dr. Phil Elliott (Research Lead for Western Cheshire PCT)

01244650559 [phil.elliott@wcheshirepct.nhs.uk](mailto:phil.elliott@wcheshirepct.nhs.uk) or

Helen Newell (Research Lead for Cheshire & Wirral Partnership Trust)

01516047333 [helen.newell@cwpc.nhs.uk](mailto:helen.newell@cwpc.nhs.uk) or

Your doctor or nurse.

If you remain unhappy and wish to complain formally, you can do this through the NHS Complaints Procedure (or the University of Chester complaints procedure). Details can be obtained from the GP practice or the University of Chester as applicable.

If you are harmed by taking part in this research project, there are no special compensation arrangements. If you are harmed due to someone's negligence (but not otherwise), then you may have grounds for legal action, but you may have to pay for this.



## **Will my taking part in this study be kept confidential?**

The doctor or nurse who sees you will know that you are taking part in the study because they have agreed to have the interview recorded (so long as you have consented also).

However, they will not see your interview in full or be able to see which individual has made what comments.

We will keep all of this information in a safe place, but would not tell the doctor or nurse

what you told us – unless it

We would not do this without

we get about you is kept



was important for your health.

asking you. All the information

confidential (so no-one apart

from the researchers [Hazel Chapman, Andrew Lovell & Ros Bramwell] can find out about anything personal to you).

## **What will happen to the results of the research study?**

We will talk about what we find out with doctors and nurses so that they can comment on it and look at any ideas to make sure that people with a learning disability get the best

possible care. We will also talk about our findings with people who have taken part to find

out what they think about the ideas we have. Then we will write about the study and

publish it in journals so that other doctors and nurses can use the ideas to help them to

care for the health needs of people with a learning disability. We will also

talk about our findings to local Partnership Boards and present it at

conferences to other health care professionals.



## **Who is organising and funding the research?**

It is funded and overseen by the University of Chester, who liaise with the Research & Development Offices of the Western Cheshire Partnership Trust and the Cheshire & Wirral Partnership Trust, and with the individual GP practices involved.

**Who may I contact for further information?**

The main researcher is Hazel Chapman. Telephone her at the University of Chester Faculty of Health & Social Care on 01244 513385 or on her direct telephone number: 01244 511626 or e-mail [h.chapman@chester.ac.uk](mailto:h.chapman@chester.ac.uk)

Please keep this information sheet in case you need it in the future.

**Thank you for your interest in this research**



## **Appendix 4: Consent Form – Study 1**

### **Consent form**

**Title of Project:**                      **Health Consultation Experience for Person  
with a Learning Disability**

**Name of Researcher:**        **Hazel M Chapman**

Please initial  
box

- |   | P*                       | W*                       |
|---|--------------------------|--------------------------|
| 1.    I confirm that I have read and understood the participant information sheet, dated 12.10.2009, for the above study and have had the opportunity to ask questions.         | <input type="checkbox"/> | <input type="checkbox"/> |
| 2.    I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason and without my care or legal rights being affected. | <input type="checkbox"/> | <input type="checkbox"/> |
| 3.    I agree to take part in the above study.  | <input type="checkbox"/> | <input type="checkbox"/> |

_____	_____	
Name of Participant	Date	Signature
_____	_____	_____
Name of Person witnessing Informed consent	Date	Signature
Hazel M Chapman	_____	_____
Researcher	Date	Signature

\*P= Participant

\*W = Witness – Please note, if participant is unable to sign form but gives verbal agreement to participate, the witness will sign to confirm this.

Witness signs to confirm that the information sheet has been explained to

## ***Appendix 5a: Pre-consultation Interview Schedule***

- Check that the participant is physically comfortable – do they know where the toilet is, want a drink of water or have any needs in terms of glasses, hearing aids?
- Start with simple revision of the research, what it's for and what it involves.
- Reminder that the conversation will be audio-recorded.
- Reminder that the participant can call a stop to the interview at any time.
- Reminder that the participant can withdraw from the study at any time without any effects to their healthcare.
- Check participant is happy to continue at 10-15 minute intervals, or if they seem restless, tired or disengaged. If they seem upset, gently discontinue the interview – ask if they wish to withdraw altogether from the study.

### **Main questions and subsidiary prompt questions**

After (Barry et al., 2000)

- ❖ What do you think your doctor/nurse appointment is for?
  - Why does the doctor/nurse want to see you?
  - What do you think might happen today/tomorrow?
- ❖ Do you have any health problems or illness
  - Is there anything about your body that worries you?
- ❖ Do you worry about a particular illness?
  - What do you think you might have “wrong” with you?
  - Are you worried about this?
  - Why? What do you think might happen?
- ❖ Is there anything you think the doctor/nurse could do for you?
  - What would you like them to do for you?
- ❖ Is there anything you do NOT want the doctor or nurse to do for you?
  - Is there anything you don't like about seeing the nurse or doctor?
  - What do you think could happen that you might not like?
  - Are you worried about any questions or tests or treatments?
- ❖ Here are some ideas about what could happen after seeing a doctor or nurse (show picture cards). Do you expect any of them to happen to you? If so, which ones?
  - Why do you think the doctor/nurse might suggest this?
  - Is there anything you would like? Why?
  - Is there anything you don't want or don't need?

- ❖ Is there anything you think it is important to talk about with the doctor/nurse?
  - What do you think it might be [what do you think is wrong?]
  - Have you taken anything for it? (medicine, special diet, exercise)
  - Have you talked this over with anyone?
  
- ❖ Have you thought of anything else you'd like to talk to the doctor/nurse about?
  - Any feelings you think they could help with?
  - Any friendships or relationship problems?
  - Are you happy where you live?
  - Do you worry about your health? Have you had aromatherapy?
  
- ❖ Do you have any problems related to your disability that the doctor/nurse could help with?
  - Physical
  - Psychological
  - Social
  
- ❖ Is there anything else you would like to say?

**Appendix 5b: Interview Question Pictures**

<p>Reassurance</p> 	<p>Advice</p> 
<p>Information</p> 	<p>Diagnosis</p> 
<p>Finding out what is wrong</p> 	<p>Referral to a specialist</p> 
<p>Tests</p> 	<p>Investigations</p> 

## **Appendix 6: Post-consultation Interview Schedule**

- Check that the participant is physically comfortable – do they know where the toilet is, want a drink of water or have any needs in terms of glasses, hearing aids?
- Start with simple revision of the research, what it's for and what it involves.
- Reminder that the conversation will be audio-recorded.
- Reminder that the participant can call a stop to the interview at any time.
- Reminder that the participant can withdraw from the study at any time without any effects to their healthcare.
- Check participant is happy to continue at 10-15 minute intervals, or if they seem restless, tired or disengaged. If they seem upset, gently discontinue the interview – ask if they wish to withdraw altogether from the study.

## **Main questions and subsidiary prompt questions**

After (Stevenson et al., 2000)

- ❖ What did you talk about with the doctor/nurse?
  - Physical health problems?
  - Mental health problems?
    - Identify each problem talked about
    - For each problem, what was the outcome?
    - Were you pleased with the outcome?
    - Would you have preferred anything else to happen?
- ❖ Were you given any health advice? (Where answer yes, ask what advice and why it is good for them)
  - Diet?
  - Exercise?
  - Fluid intake?
  - Related to prescription medicine?
  - Related to taking in caffeine, alcohol, non-prescription medicine, drugs?
  - Advice about sexual health?
  - How did you feel about this? (after each one)
- ❖ Were you given a prescription for any new medicine?
  - Were you happy with that? (If yes, why if no, why not?)
  - What was the medicine called? Did the doctor/nurse tell you?
  - What does the medicine do?
  - Did the doctor/nurse offer you any other treatment instead?
  - Did you have any questions about your medicine?
  - Did you ask the doctor/nurse any questions or did they give you the answers without asking?
- ❖ Were you given a prescription for changed doses of medicine you were already taking?
  - Were you happy with that? (If yes, why if no, why not?)
  - What was the medicine called? Did the doctor/nurse tell you?
  - What does the medicine do?

- ❖ Was there anything that you wanted to talk about but didn't get around to?
  - If yes, what?
    - Why didn't you talk about it?
  
- ❖ Did the doctor/nurse say you should have any tests or investigations?
  - If yes, what tests?
  - For each one, what are they for?
  - Where and when will you have them / get the results?
  
- ❖ Did you enjoy talking with your doctor/nurse?
  - If yes, why?
  - If no, why not?
  
- ❖ Could the doctor/nurse have done anything to make the health check better?
  
- ❖ When you talked about your health, or having tests, or taking medicines or any other kind of help, did the doctor/nurse ask what you thought about it?
  - Were you given any choices?
  - Did you make any decisions?
  
- ❖ Would you like to see the doctor/nurse again in a year's time? (Ask why)
  
- ❖ Could the doctor/nurse do anything different to make the health check better for you? (What?)
  
- ❖ Could the doctor/nurse do anything different to make the health check better for other people with a learning disability? (What?)
  
- ❖ Which problems did the doctor/nurse help most with?
  - Physical
  - Psychological
  - Social
  
- ❖ Which problems did the doctor/nurse help least with?
  - Physical
  - Psychological
  - Social
- ❖ Is there anything else you would like to say?



## Appendix 7: Ethics Approval Substantial Amendment 1 – Feb 11



### National Research Ethics Service North West 1 Research Ethics Committee – Cheshire

Research Ethics Office  
Barlow House  
3rd Floor  
4 Minshull Street  
Manchester  
M1 3DZ

Tel: 0161 625 7815

07 February 2011

Mrs Hazel M. Chapman  
Senior Lecturer  
Faculty of Health & Social Care  
University of Chester  
Parkgate Road  
Chester  
CH1 4BJ

Dear Mrs Chapman

**Study title:** Agendas, experience and health outcomes related to the primary health care consultation for people with a learning disability - exploration and evaluation  
**REC reference:** 10/H1017/2  
**Amendment number:** Substantial Amendment 1  
**Amendment date:** 03 February 2011

- The proposed amendment is to obtain additional information to be collected from service users in the day service setting.

The above amendment was reviewed by the Sub-Committee in correspondence.

#### Ethical opinion

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

#### Approved documents

The documents reviewed and approved at the meeting were:

Document	Version	Date
Notice of Substantial Amendment (non-CTIMPs)	Substantial Amendment 1	03 February 2011
Letter from Sponsor notifying that they are aware of proposed amendment		27 January 2011
Participant Information Sheet	3	03 February 2011
Protocol	3	26 January 2011

This Research Ethics Committee is an advisory committee to the North West Strategic Health Authority  
The National Research Ethics Service (NRES) represents the NRES Directorate within  
the National Patient Safety Agency and Research Ethics Committees in England

**Membership of the Committee**

The members of the Committee who took part in the review are listed on the attached sheet.

**R&D approval**

All investigators and research collaborators in the NHS should notify the R&D office for the relevant NHS care organisation of this amendment and check whether it affects R&D approval of the research.

**Statement of compliance**

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

**10/H1017/2:**

**Please quote this number on all correspondence**

Yours sincerely



**Miss Shehnaz Ishaq  
Committee Co-ordinator**

E-mail: shehnaz.ishaq@northwest.nhs.uk

*Enclosures:*                      *List of names and professions of members who took part in the review*

*Copy to:*                         Mark Helsdon – The University of Chester

## **Appendix 8: Ethics Approval – Substantial Amendment 2 – April 13**



### **NRES Committee North West - Cheshire**

HRANRES Centre North West  
Barlow House  
3rd Floor  
4 Minshull Street  
Manchester  
M1 3DZ

Tel: 0161 625 7816  
Fax: 0161 625 7299

30 April 2013

Mrs Hazel M. Chapman  
Senior Lecturer  
University of Chester  
Faculty of Health & Social Care  
University of Chester, Parkgate Road  
CHESTER  
CH1 4BJ

Dear Mrs Chapman

**Study title:** Agendas, experience and health outcomes related to the primary health care consultation for people with a learning disability - exploration and evaluation  
**REC reference:** 10/H1017/2  
**Protocol number:** N/A  
**Amendment number:** 2  
**Amendment date:** 04 April 2013  
**IRAS project ID:** 6457

#### **Overview of amendment**

Amendment to conduct interviews with more people directly and individual about their health care experience.

The above amendment was reviewed [at the meeting of the Sub-Committee held in correspondence.

#### **Ethical opinion**

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

#### **Approved documents**

The documents reviewed and approved at the meeting were:

Document	Version	Date
Interview Schedules/Topic Guides	2	27 March 2013
Participant Information Sheet	2	27 March 2013
Notice of Substantial Amendment (non-C TIMP s)	2	04 April 2013
Protocol	4	27 March 2013

A Research Ethics Committee established by the Health Research Authority

### **Membership of the Committee**

The members of the Committee who took part in the review are listed on the attached sheet.

### **R&D approval**

All investigators and research collaborators in the NHS should notify the R&D office for the relevant NHS care organisation of this amendment and check whether it affects R&D approval of the research.

### **Statement of compliance**

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at <http://www.hra.nhs.uk/hra-training/>

**10/H1017/2:**

**Please quote this number on all correspondence**

Yours sincerely



**Mr Jonathan Deans**  
**Chair**

E-mail: [nrescommittee.northwest-cheshire@nhs.net](mailto:nrescommittee.northwest-cheshire@nhs.net)

Enclosures: List of names and professions of members who took part in the review

Copy to: Dr Phil Elliott, Cheshire & Wirral Partnership NHS Foundation Trust  
Clinical Governance Team  
Mark Helsdon

## **Appendix 9: Original Data Coding and their Destinations**

**Table 18: Initial codes/focused codes in order of identification**  
(Grey-highlighted codes not used in final analysis)

1. ?No control / self-efficacy
2. Worry over health future health / ?Trajectory of illness
3. Labelling and stigma
4. Psychosocial health care/needs, e.g., understanding of health concerns, acknowledgement of situation, seeks reassurance / health information, possibly related to carer (?)
5. Cues and prompts in consultations
6. Role of the other (parent, carer) in health / health consultation - ?transactional analysis, ?systems theory
7. Sexual and reproductive health
8. Health professional consultation strategies (and influences on the experience)
9. The body – self-concept and medicalisation of self (relates back to control)
10. Gender issues in the consultation
11. Service user and parent/carer health service expectations; patient satisfaction
12. Physical examinations / tests within health consultations
13. Past experience of health / social care
14. Infantilisation – use of language or approach to put the service user in the role of the child
15. Fear of disclosure – a sense that they will “get into trouble” for disclosing anything about their medical care and difficulty in expressing negative views about their care<sup>4</sup>
16. Health outcomes – any diagnoses, tests, advice or other health outcomes from the consultation
17. Anxiety related to health care/ health consultations
18. Understanding gap – barriers to satisfaction / good health outcomes
19. Psychiatric care – effects on perceptions about doctors and nurses of experiences with psychiatric care services
20. Health checks provided by other services
21. Multiple service providers can be problematic for service user
22. Individual personality/relationship with health professional
23. Lifestyle advice can be aversive
24. Home remedies / self-management strategies / lay theories of health / illness
25. Agendas not expressed
26. Health facilitator
27. Interview experience
28. Service provider expectations
29. Motivation for health behaviours
30. Specific disability needs / effects
31. Habituated
32. Anxiety-reducing strategies
33. Agendas expressed
34. Ease of access to services
35. Emotional security with provider
36. Aging or ill parent(s)
37. Multi-professional working / communication

<sup>4</sup> Added 09.05.13 – P8, T6, 372-405

38. Informal support
39. Autonomy / choice
40. Other stressors affecting health
41. Health behaviour / change
42. Health screening
43. Knowledge of healthy behaviours
44. Formal support
45. Barriers to behaviour change
46. Role confusion (professional)
47. Medicines review / management
48. Listening
49. Perceived competence of health professional
50. Guilty over health (behaviours)
51. Control (is / feels / wants to be in control of own health)
52. Medicalisation of person's individual behaviour / personality
53. Involvement in health care provision
54. Looks after you (good nurse)
55. Talks to you nicely (good nurse)
56. Only does what you tell her to do (good nurse)
57. Lack of choice / autonomy (bad nurse)
58. Lack of involvement / communication (bad hcp / experience)
59. Involvement in communication / inclusion
60. Body weight – big issue
61. Friendly health care professional (good)
62. Positive health advice
63. Embarrassment
64. Consultation time / length – waiting time
65. Findings / test results – are they given / explained
66. Trust health professionals
67. Health professionals in control
68. Health professional is expert
69. Communication barriers
70. Strategies to achieve their agendas
71. Training need

**Table 19: Destination of identified codes/themes in final analysis**

Discarded Theme	Reason / Destination
?No control / self-efficacy	Some aspects of this were related to outside the consultation experience, while others fitted into other categories, such as <i>Individual personality / relationship with health professional; Strategies to reduce anxiety; Involvement in communication / inclusion</i>
Worry over health future health / ?Trajectory of illness	Again, this broke down into other categories, particularly <i>Psychosocial health care/needs / Labelling and stigma</i>
Health professional consultation strategies (and influences on the	Some aspects of this went into various sections of <i>Emotional security with the</i>

experience)	<i>health care professional</i> , while some went into <i>Strategies to overcome anxiety</i>
The body – self-concept and medicalisation of self (relates back to control)	Self-concept underlies much of the analysis, so its use as a theme was not appropriate. Some discussion of self-concept can be found in <i>Informal support</i> and the fears that health consultations and checks can raise and medicalisation of the body can be found in <i>Anxiety, embarrassment and gender related to health encounters</i> as well as in <i>Expressing agendas</i>
Service user and parent/carer health service expectations; patient satisfaction	This is mostly contained within <i>Past experiences and current perceptions of health care</i> , but is also found throughout the analysis
Health outcomes – any diagnoses, tests, advice or other health outcomes from the consultation	This was discussed in <i>Expressing agendas, Explanations and understanding in health consultations</i> and <i>Anxiety, embarrassment and gender related to health encounters</i>
Home remedies / self-management strategies / lay theories of health / illness	The small amount of data for this was contained within <i>Expressing agendas</i>
Service provider expectations Positive health advice	These were discarded once the methodology changed and audio-recording of the consultation was stopped. Where service provider expectations were relevant, as seen from the service user perspective, they were included in the appropriate category, mainly <i>Lifestyle advice can be aversive, Involvement in communication / inclusion, Expressing agendas, Informal support and Health facilitator role, Strategies to overcome anxiety</i>
Specific disability needs / effects	Not written as a separate category, but included in <i>Expressing agendas, Individual personality / relationship with health professional; Multiple service providers; Informal support; Health facilitator role, Anxiety, embarrassment and gender related to health encounters; Strategies to overcome anxiety</i> and <i>Past experiences and current perceptions of health care</i>
Ease of access to services	There was only a small amount of data on this, but it was looked at more as it affected perceptions of the person's value and cost to the GP
Aging or ill parent(s)	Insufficient data
Health screening	Discussed in relation to <i>Explanations and understanding; Expressing agendas; Health facilitator role; Anxiety, embarrassment and gender related to health encounters;</i>

	<i>Strategies to overcome anxiety and Past experiences and current perceptions of health care</i>
Health behaviour / change	These fitted more into an analysis of health behaviours, rather than an understanding or the person's experience, although some responses to behavioural advice went into <i>Lifestyle advice can be aversive</i>
Knowledge of healthy behaviours	
Motivation for health behaviours	
Barriers to behaviour change	
Role confusion (professional)	<i>Discussed in multiple service providers</i>
Medicines review / management	Not discussed except where relevant to interaction – little data
Perceived competence of health professional	Small amount of data spread throughout thesis
Looks after you (good nurse)	<i>Discussed in Friendly health professional / talks to you nicely</i>
Talks to you nicely (good nurse)	
Only does what you tell her to do (good nurse)	
Lack of choice / autonomy (bad nurse)	<i>This was discussed in Involvement in communication / inclusion, Anxiety, embarrassment and gender related to health encounters; Strategies to overcome anxiety and Past experiences and current perceptions of health care</i>
Lack of involvement / communication (bad hcp / experience)	<i>This was discussed within Involvement in communication / inclusion</i>
Body weight – big issue	<i>This was discussed in Lifestyle advice can be aversive</i>
Health professionals in control	<i>This was discussed within Involvement in communication / inclusion</i>
Health professional is expert	
Training need	Not relevant to service user perspective



## ***Appendix 10: Member Check***

### **Being Listened To**

Lisbet and Daniel both agreed that it was very important to be listened to and expressed how frustrating and upsetting they both found it when people pretended to have understood them because they were too embarrassed to admit they had not understood them. Lisbet prefers telephone consultations because her voice is better on the telephone and she finds that people understand what she is saying more easily. However, both Janet and Daniel prefer it if people ask them to repeat what they said, or to say it in a different way so that they can understand. Lisbet's mum understands that people can be embarrassed to do this, but thinks that health professionals should be able to overcome this feeling for the sake of the service user being heard. Daniel speaks very quietly and has a stammer that worsens in stressful situations, so it is important for people to sit at the same level as him and close to him, so that they can hear him more easily. Lisbet thinks health professionals should be honest, say they don't understand and ask if it is alright to discuss it with the carer. Daniel is happy for someone else to sit with him and help with the conversation, but does not want the person to pretend they have understood, and make assumptions. Lisbet would rather not have to go to the doctor – Lisbet says her mum understands her, and that is very important. Lisbet had a very good experience of a four-week stay in hospital, where her mum stayed with her all the time, but the staff were brilliant, and Lisbet would like to go back there. They talked to her, and did not talk at her.

### **Friendliness of Health Professionals**

Daniel does not find doctors friendly, but hopes the doctor would take his word and treat him seriously. He likes his nurses because they have "common sense" and don't talk down to him, but treat him like a human being. Lisbet liked a male nurse in hospital because he made her laugh, and having a good relationship with nurses is important, and a bit of banter releases the tension and makes it easier. Lindsey does not know if her doctor is friendly – "doctor sometimes speaks to me, but doesn't ever smile on his face, which makes me nervous. Some doctors smile – my last doctor, I liked him; he understands what I'm saying. This one knows what he's doing, but he never smiles". Edmund says that "people I see always have a bit of a smile on their face."

### **Explanations and Understanding**

When she was consented for a leg operation in hospital, twelve months ago, she was informed in detail about everything that could go wrong, making her so scared that she has been unable to attempt to walk yet, and has only just started transferring herself. However, she needs to understand everything that is done to her and the reasons for it, or she will worry about it.

### **Involvement in Communication/Inclusion**

Ella (through picture board) was happy when she went to see the doctor. She wants the doctor to talk to her, and the doctor does. Ella prefers to see a doctor if she is ill. Jo goes to the doctor with her mum, who has a car that is adapted for her wheelchair. Lisbet likes her doctor and nurse because they talk to her rather than her carer, which makes her happy. Lisbet's mum commented that other parents might not be aware of the changes and that health professionals should be talking more with the service user now. Simon had to have a blood test, he had no choice. He cannot choose who he sees; he saw a man doctor, but prefers to see a woman doctor, as he likes them better.

### **Secure Relationship/Knowing the Health Professional**

Daniel prefers to see his own doctor, whom he knows. They know him better and know about his speech difficulty. Lisbet thinks that if health professionals did not know her, they would not know how to understand her and she would not have confidence in them. She likes seeing the Sister best because she knows all about Lisbet. Lisbet thinks it is really important that people can understand her. Lisbet's mum thinks health professionals need to have some learning disabilities experience to make care and communication good. Edmund thinks they need to know you inside out – the relationship is very important. His new nurse is very nice, but is still building up that trust, and it will take a while. He was hurt when the practice nurse retired as she has known him and his family a long time. It takes Edmund a long time to learn to trust new people. Simon says the doctors ask his Dad the questions. Dad asks for more prescriptions and the doctor signs them. Simon likes his doctor, knows him well, has known him a long time and he says "I'll see you next year" – he sees the same doctor every year, and he looks after his mum and dad as well. They like and trust him, as does Simon.

### **Consultation Length**

Edmund says that the health professional can explain things properly in the time they have because the more they see you, the more that relationship and trust build up.

### **Explanations and Understanding**

Edmund has had explanations supported with “easy-read” leaflets and Catherine, who goes to the same GP practice, says that when they explain it is it easy to understand. Edmund explains that they have known the practice nurse “since we were quite young, so we’ve bonded, so she understands us and knows how to say it”. He would like health professionals to tell him if they do not understand him, and he would tell them if he did not understand them. Lindsey, who goes to a different practice, is not given leaflets, and says the doctors do not speak to her, but speak to her carers because she does not understand what they are saying. She says sometimes they speak to her like a child, but at one hospital, the doctor did explain things to her. However, when she went to hospital with a broken arm and needed an operation, her father was furious because they moved it to the extent she was screaming and fainted, and he wrote a letter of complaint. At her GP practice, she said one doctor was very nice to her, but the other doctors spoke to her Mum, not to her, which made her sad. Lindsey likes it when they use words she can understand and show her equipment they will use. Edmund and Catherine also like that. Edmund now understands what the nurses and doctors are telling him – “I didn’t used to, but I’ve got more understanding of my diabetes, partly through experience. Nobody can help you unless you help yourself”, but the health facilitator and doctors have helped him to understand.

### **Embarrassment**

Lindsey feels embarrassed when she sees the doctor, and cannot tell them anything to do with ladies’ problems, when she needs to talk to a lady nurse or doctor. She has never been asked if she wants to see a lady or man doctor, but would like to be. If she has ladies’ problems, she tells the nurse and the nurse tells the doctor. She trusts the nurse, but not the doctors. Catherine does not mind. Edmund is not bothered – when he had a problem down below, he was asked which he preferred, but he “just wanted to get it out of the way”. If Lindsey did not like the doctor, she would not say it to the doctor, but would tell the carer.

### **Is Lifestyle Advice Aversive?**

Catherine and Edmund have the same doctor, and according to Edmund, “he’s a very good doctor, but very strict and straightforward. He doesn’t think about you having a disability – found it difficult at first, but he was right, and now I like it because I’m straightforward as well. He just tells it how it is”. Lindsey says “advice can make me nervous, scary – can’t tell the doctor how he makes me feel. I could say it to the nurse. It would be better if I could see the doctor with the nurse there. I see the nurse more than the doctor, because I prefer the nurse. She’s clear, and she understands what I’m saying to her.” Simon says the men doctors tell him off – because he drinks too many sugary drinks and should drink water or tea. He had a urine test the last time to test for sugar in his urine. Simon minds if doctors and nurses are pleased with his blood sugars – he likes them to be happy and pleased with him. He likes to know the results of his urine & blood tests, weight and b/p – the doctor did tell him. He gets tablets for epilepsy and high blood pressure from the doctor. He doesn’t like to be involved in making decisions, but he knows he needs to take his tablets to stop having fits. He needs to drink more before his blood tests so that they can get the blood. Trusts doctors and nurses. Never been involved in interviewing them. He feels happy when he is given lifestyle advice – eat more fruit and yoghurt. Go the gym and the swimming baths – which he likes – on doctor’s advice. Simon likes to make decisions about his health, and he tells people if he doesn’t feel well, and they decide if he should see a doctor. Doctor is pleased with him if he hasn’t been drinking beer. Sometimes, he drinks too much water, so he needs to drink in moderation. He’s happy when the doctor’s happy with him, but he’s upset when the doctor is not pleased with him.

### **Multiple Health Providers**

When asked about the differences between health professionals, Edmund said “a doctor’s more educated than a nurse, he’s more higher up, I think he does know more”. Lindsey thinks that doctors are more important, “nurses are good, but doctor’s got loads of information about what he’s doing, but he never smiles”. She thinks the doctor is important because he’s looking after her stomach.

### **Health Facilitator Role/Role of the Other**

The health facilitator helps Edmund mainly “with the health side. If there’s something I don’t understand, I can ask HF, and he can explain it to me in a way I can understand”. Catherine tends to see the doctor with a carer (paid). Catherine has two very nice doctors, and the HF was involved in their GP training about the needs of people with a

learning disability. Edmund agrees that the service at that practice is good – the HF put a lot of work into it; they've put a lot of work into making reasonable adjustments – time of appointments, easy-read leaflets, take pictures with service users about mammograms / breast screening, and about going into A&E, about having a blood test – a picture journey, for the hospital and practice to use about what happens. Care staff take Simon to the doctors and go in with him, which he likes – he goes with ..., a man, who understands him, and he likes. The carer talks to the doctor, but the doctor listens to Simon, and Simon understands what the doctor says.

### **Hospital Experience**

Catherine was in hospital two years ago, and didn't like it. The nurses were very nice the last time. She thinks the doctors and nurses are very good to make her better. Edmund does not like hospitals because he gets too warm and claustrophobic, and the beds are uncomfortable. Catherine prefers her own bed as well. Edmund does not like needles; the feeling "goes through me". Lindsey loathes needles. Neither of them likes hospital. Vicky does not like the food either.